A joint open letter from patients with empty nose syndrome and caring people from all walks of life to the National Health and Family Planning Commission

Original Sun Sulin Empty Nose Syndrome Care Center 2018-03-09 09:03

Joint background:

Since the 1990s, rhinitis surgery has been widely popularized and reached its peak around 2010, but it has resulted in a large number of patients with empty nose syndrome. Because they cannot bear the inhuman torture and lose the ability to work, there is no treatment in the world, causing patients with empty nose syndrome to completely lose confidence and hope in life. Sudden death and suicide of patients occur from time to time. In 2016, Beijing painter and poet Di Yue Mei, Dalian boy Liu Wentao, and Xinjiang girl Zhang Rui committed suicide by jumping off the building one after another. Around 2013, an 18 year old high school girl in Yuncheng, Shanxi, and a 30-year-old mother in Xiangyang died suddenly while sleeping after rhinitis surgery... The occurrence of these incidents shocked everyone. As a patient with empty nose syndrome, we must send out our cry for help to all walks of life, so that governments from all walks of life and all levels of society can see the survival symptoms of patients with empty nose syndrome, and to provide relief to every empty nose patient who is suffering from the disease. A hope and a glimmer of hope for the families of patients with the disease. We want to survive well! We need to research treatments!

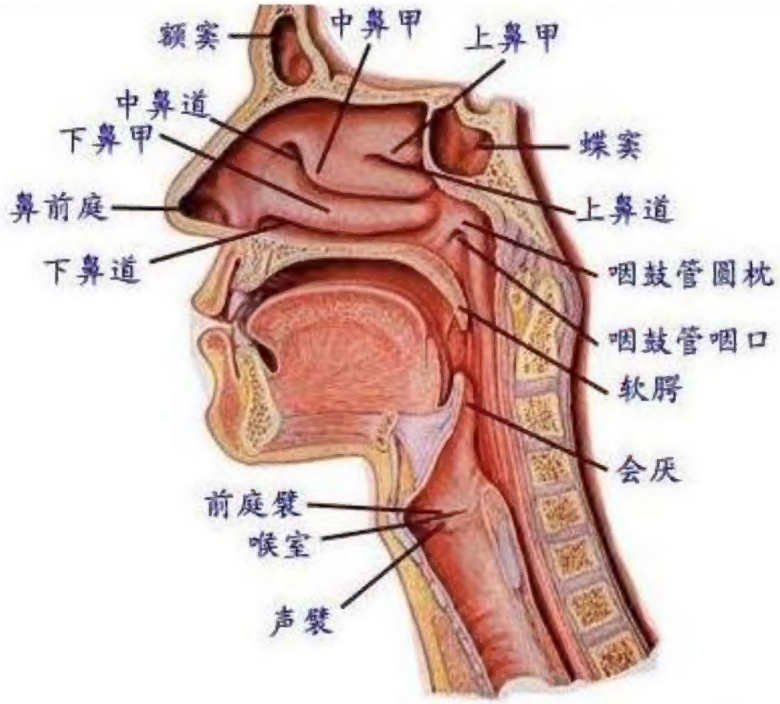
The following is an open letter jointly signed by patients with empty nose syndrome to the National Health and Family Planning Commission. We hope that people from all walks of life will join us in our loving joint signature and extend your helping hand. Your message and signature will help make empty nose syndrome more accessible. Patients are one step closer to hope!

Dear National Health and Family Planning Commission:

Hello! We are a group of patients with empty nose syndrome, voluntarily formed by patients and their families. Our purpose is to provide assistance, psychological counseling and emotional care to patients, so that everyone can help and care for each other, be full of positive energy, build confidence and harmony in overcoming the disease. Doctor-patient relationship. At the same time, we will popularize the knowledge and preventive measures of empty nose syndrome to the public. We do our best to find research and treatment methods for patients with empty nose syndrome, strive to provide patients with medical treatment, gain widespread recognition and support from society, and promote social harmony and progress.

Empty nose syndrome was first proposed by American doctors. It has only gradually become known to the Chinese people in recent years, but it has not yet attracted the attention and recognition of the medical community.

Empty nose syndrome: Empty nose syndrome or empty nose syndrome, abbreviated as empty nose syndrome, English: Empty Nose Syndrome, abbreviation: ENS. Empty nose syndrome is an iatrogenic chronic debilitating disease. This disease is mainly an acquired disease, mainly caused by external causes, mainly caused by turbinate surgery, corrosion, trauma, etc., such as: turbinate removal, plasma ablation, drug corrosion and other surgeries, as well as car accidents, burns, chemical corrosion, cosmetology, etc. Respiratory dysfunction and a series of systemic complications caused by external force injuries. It is a disease with serious consequences, irreversible, deteriorating and incurable, and is a global problem.



鼻腔、口腔、咽和喉的正中矢状面

What are the symptoms of empty nose syndrome?

Collected based on descriptions from otolaryngology experts at home and abroad and descriptions of patients' own symptoms:

Most patients with empty nose syndrome suffer from dry nose, nasal pain, large and cold ventilation, dry and crusted nasal cavity, white and dry mucous membranes, atrophied turbinates, wide nasal cavity, cough, nasal discharge, runny nose, and thick nasal secretions. , dry and sore throat, dry eyes and blurred vision, hair loss, ear blockage, headache, dizziness, fatigue, drowsiness, memory loss, lack of energy, reduced work ability, inability to concentrate, depression, frustration or restlessness or irritability, Symptoms of systemic disease such as difficulty sleeping.

Severe patients may even develop dyspnea, suffocation, hypoxia, chest tightness, palpitation, shortness of breath, dizziness and weakness, backache, body pain, thickened lung texture, severe decrease in lung function, pulmonary nodules, chronic obstructive pulmonary disease, heart rate Serious complications such as disorders, osteoporosis, low platelets, hematuria, gastrointestinal discomfort, liver pain, endocrine disorders, hypertension, hyperglycemia, hyperlipidemia, severe decline in multiple organ functions, and chronic failure of systemic organs make patients feel like they are in purgatory. They are suffering, living worse than death and losing their labor force. Their quality of life is very poor and their lives are always in danger. Some patients even die suddenly. Some patients can't stand this inhuman torture and commit suicide in despair.

What is the pathogenesis of empty nose syndrome?

(1). The turbinates have functions such as sensing, heating, humidification, regulation, defense, cleaning, immunity, resonance, and nerve reflexes. After the turbinate is removed, the cavernous body, blood vessels, mucosa and nerves contained in it are correspondingly removed or ablated. The turbinate and mucosa can no longer be filled with blood, resulting in insufficient blood supply, reduced mucosal area, proportional decrease in nasal mucosal receptors, decreased nasal resistance, and decreased nasal cavity. Decreased regulatory function and destruction of gland secretion function are jointly involved in the disease. (Quoted from medical literature)

(2). Turbinates are considered to be a source of nerve growth factors. The nasal mucosa is rich in glands and receptors. After the turbinate mucosa is destroyed, the number of glands and receptors decreases. In addition, due to insufficient blood supply and decrease in nerve growth factors, Nerve regeneration and healing are difficult, the turbinates and mucous membranes will gradually atrophy, the airflow sensing and transmission functions will decrease, the reflex functions of the nose, lungs, and nose and heart will decrease, the blood gas oxygen and ability of the heart and lungs will be impaired, and in severe cases, severe methemoglobinemia will occur. That is MetHb. Because MetHb cannot carry oxygen and release oxygen reversibly. The iron ion parts that can be combined with oxygen have lost their electrons and are firmly combined with hydroxyl groups or

chlorides. The main clinical manifestations of MetHb are hypoxia and cyanosis, dyspnea, and dizziness. Severe cases can lead to death. This also explains why many patients with empty nose syndrome suffer from symptoms such as suffocation, hypoxia, difficulty breathing, dizziness and weakness. (Quoted from medical literature)

(3). Nasal resistance: 50%-80% of the entire respiratory tract resistance comes from nasal resistance. Appropriate nasal resistance helps maintain peripheral bronchial opening and alveolar expansion, thereby ensuring smooth gas exchange and maintaining negative thoracic pressure to facilitate venous return of systemic and pulmonary circulation and sufficient venous return to the heart. Normal nasal resistance during expiration helps maintain lung volume and may indirectly affect arterial oxygenation. After turbinate resection or ablation, the resistance of the nasal cavity decreases, and the pressure difference between the gas and the mucosal surface decreases, resulting in abnormal function of the nasopulmonary bronchial reflex, affecting the respiratory tract and lung function, worsening the lung function, and causing the patient to have chest tightness. Shortness of breath, difficulty breathing, or even a feeling of suffocation. (Quoted from medical literature)

(4). The latest scientific research shows that the nose and lungs together form the respiratory system of the human body. The nose is a very extended source of breathing. Damage to the source will inevitably affect lung function. The lungs are not only used for breathing, but are also a key component involved in blood production. The lungs are the site of platelet biosynthesis and a reservoir of hematopoietic progenitor cells, and are responsible for producing more than half of platelets. (See "New Function of the Lungs Hematopoiesis")

How many people have empty nose syndrome?

According to domestic and foreign experts, more than 80% of people will experience discomfort after turbinate surgery, and more than 20% will develop empty nose syndrome. There are about 300 million rhinitis patients in our country. According to theoretical calculations, the

number of patients with empty nose syndrome in our country is about 6 million. This number far exceeds the total number of patients in European and American countries. Moreover, the extent of the disease in our country is far more serious than that in other countries. Many The patient dies suddenly or commits suicide due to being unable to bear the torture.

Living conditions of patients with empty nose syndrome:

The living conditions of patients with empty nose syndrome can be described as hell. However, many of us were originally healthy people,

but because of the loss of a small turbinate, our lives have changed and we have fallen into a dark hell. Breathing, a common physiological movement, has become a luxury for us. Almost everyone has breathing difficulties. Although we appear intact, the various organs of the body cannot function normally. Everyone has a problem, all over the body. The organ lights up red.

Because of Empty Nose Syndrome, children who are still in school can no longer study normally. The originally happy family is divorced, the family is broken up, the family savings are wiped out, the prosperous career is ruined, the parents are unable to support their children, the family is unable to raise their children, and the house and land are sold. No one can look down on this feared disease. Because of Empty Nose Syndrome, our originally strong bodies collapsed and we had to lie on the hospital bed to linger. Breathing became a problem. We used to be vigorous and vigorous, but now we are unable to restrain ourselves. Our bodies are not as frail as those of an 80 year old man. We have become became the object of care.

Because of Empty Nose Syndrome, one of us fell ill and brought down the entire family. He was originally the pillar and pride of the family and the backbone of the company, but now he has completely lost his ability to work, cannot do anything, was fired by his employer, lost his ability to make money, and became With the burden and drag of our family, we have no face to see our friends and colleagues, we are isolated from the world, depressed, and only our noses remain in the world.

The medical community and society have limited awareness of empty nose syndrome:

Because empty nose syndrome has not been included in the disease catalog yet, the disease information is not transparent and public, and the teaching materials are not updated in a timely manner. Many otolaryngology doctors do not know about empty nose syndrome, and many authoritative experts also know very little about empty nose syndrome, and even medical science Physicians, doctors, medical school professors, and otolaryngologists themselves have all become victims of rhinitis

surgery. They have had turbinates removed and become members of the army of empty nose syndrome, not to mention ordinary people who have no medical knowledge. Because the disease information of empty nose syndrome is not transparent, the misdiagnosis rate and missed diagnosis rate caused by patients going to the hospital reach more than 90%. Now most rhinitis surgery patients are still kept in the dark, even if they suffer from complications after surgery, they do not know it. I am a patient with empty nose syndrome. Some patients with empty nose syndrome have even been misdiagnosed for 40 years. It was not until his children saw our popular science on empty nose syndrome online that they realized that the disease that had seriously troubled their father for many years turned out to be empty nose syndrome. However, this patient was already in his twilight years. An old man has been suffering from empty nose syndrome for almost half a century, but he has been to many hospitals over the years but still doesn't know what the problem is. There is also a patient with empty nose syndrome in Yichang, Hubei Province who has been thought to have a lung problem for many years. He has been taking respiratory drugs for many years and has not gotten better. It has even worsened. He did not understand it until he saw our popular science. There are also a few doctors who know about the disease Empty Nose Syndrome, but they dare not tell patients the truth due to various pressures. They are also confused because the turbinate plasma ablation method was once very popular, and many otolaryngology departments in many hospitals spent a lot of money to introduce it. Equipment and technology, but I didn't expect that foreign advanced technology has such big flaws. How do you ask these doctors to face his (her) patients? how to explain? This is indeed a difficult problem! As patients, we understand very well that after all, the current medical technology does not understand the human body well enough. The application of medical technology is also constantly exploring and practicing, and it is changing with each passing day. It is normal for a new technology to have flaws in its application. But if there are deviations, please correct them in time so that we can treat the disease and provide treatment and relief. After all, there is such

a large group of people with empty nose syndrome, and it is a social problem that cannot be ignored.

Due to the limitations of existing scientific and technological means and the scope of department diagnosis and treatment, it is difficult for most patients with empty nose syndrome to detect turbinate damage when they visit the hospital. However, in fact, turbinate damage in patients with empty nose syndrome often causes problems in other organs. For example: lung function, blood test, urine test, heart, blood pressure, blood sugar, etc. However, since the problem is caused by the nose, it is difficult for most doctors to connect the problem of the nose with the symptoms of other organs in the body, resulting in empty The diagnosis of patients with rhinitis can only rely solely on the examination of the turbinates, rather than a comprehensive diagnostic examination in conjunction with other organs, which also makes identification and disability determination difficult. Many doctors therefore believe that patients with empty nose syndrome have mental problems and are suffering from depression. The initial sympathy of family members gradually turns to anger and incomprehension. They feel that since the doctors have checked and said there is nothing wrong, it must be someone in their own family who is at fault. Making trouble unreasonably. Some families even forcibly send patients with empty nose syndrome to psychiatric hospitals for treatment.

Because the description and diagnosis of empty nose syndrome are almost blank in the current textbooks, patients with empty nose syndrome cannot be evaluated when they enter the lawsuit and cannot receive compensation. The court's reason for rejection is that it is impossible to conduct a disability appraisal, and the appraisal agency withdrew the evaluation. The reason is that there is no corresponding disability assessment standard. Because there is no statutory disability, many patients with empty nose syndrome who have lost their jobs cannot obtain disability certificates, receive subsistence allowances and receive assistance, and the entire group is trapped in an isolated and helpless situation. While other disease groups are calling for the inclusion of drugs to treat diseases in medical insurance, we don't even have a name

for the disease, let alone research and treatment. Because this disease is not included in the disease catalog, no institution is willing to study it. We have become hopeless orphans. We watch helplessly as our patients with empty nose syndrome struggle in the abyss and suffer in a purgatory that is worse than death. At a loss what to do. Because there is no hope of treatment and life, many patients commit suicide or go to extremes in despair.

Because rhinitis surgery is easy to make money and profits are easy, and patients cannot be identified and compensated for their injuries, many private hospitals have made good use of this legal gray area, advertising on the Internet to solicit customers, and guiding people to the wrong hospital to receive this kind of surgery. Wrong surgery, most of the victims were teenagers. However, these people were originally in their prime and in the prime of life, a good age for starting a career, but their lives were ruined by Empty Nose Syndrome. They turned from being the backbone of creating social value and wealth into a burden on society and a big society. question. Although many private hospitals received a small profit of several thousand yuan at that time, they brought immeasurable losses and burdens to the entire society and caused extremely serious social problems.

The difficulties we face when registering an empty nose syndrome charity organization:

In order to include Empty Nose Syndrome in the list of diseases, to research and treat Empty Nose Syndrome, to help and rescue this disaster group, and to research and treat Empty Nose Syndrome, Sun Sulin and Tao Jie even sold their only house in Shanghai at a low price. Over the past four years, they have been calling for us to run this organization better and improve its credibility. We have been working hard to register and establish it as a formal public welfare organization, from Beijing to Guangdong to Shenzhen to Hubei to Guangzhou to Shanghai..., but the registration But the road was full of hardships and frustrations. We were turned away countless times. The reply was that it was not approved by the Health and Family Planning Commission, the business supervisory unit. We also went to the relevant local Health and Family Planning Commission, and the answer was that it was not under their control. We really understand. Many people feel confused and helpless. They often sit in the halls of civil affairs bureaus at all

levels or in front of the gates of the National Health and Family Planning Commission, faltering, not knowing where to go?

As patients in a large country, we often feel ashamed. Nowadays, European and American countries have already registered public welfare organizations for patients with empty nose syndrome, but we don't even have a name for the disease. Every time we face questions and inquiries from foreign patients and public welfare organizations, we can only smile bitterly or avoid talking. Because there is no formal public welfare organization, every time we go out to communicate with other organizations and individuals, we are always suspected. Who do we represent? Who can we represent? Who are we ourselves? Because there is no organization, it is difficult for us to raise donations; because there is no organization, we have no credibility in what we do and say; because there is no organization, it is difficult for us to carry out our activities; because there is no organization, we are not recognized and paid attention to; ... ...There are too many difficulties and difficulties. I hope that the Health and Family Planning Commission, as the competent authority, can approve us to establish an organization for patients with empty nose syndrome, and I hope that the Ministry of Civil Affairs can be open minded and accept us.

Voices and expectations of patients with empty nose syndrome:

In order to reduce the burden on society, and at the same time, for the hope and confidence that millions of people with empty nose syndrome can rekindle their lives, for social harmony and tranquility, for us to return to society and work, and for the health and happiness of countless families, we appeal to the society People from all walks of life have paid attention to the problem of empty nose syndrome. There are 300 million rhinitis patients in China. Who can guarantee that they will not become the next empty nose syndrome? With tears in my eyes, I once again request the National Health and Family Planning Commission to listen to our voices, lend a helping hand, pay attention to our appeals, and give patients with empty nose syndrome a way out and hope:

1. Request the National Health and Family Planning Commission to include "empty nose syndrome" in the disease catalog so that about 6

million patients can be diagnosed.

2. Request the National Health and Family Planning Commission to provide disability levels and identification standards for empty nose syndrome based on the degree of disability, so that identification agencies and judicial institutions have a clear basis, so that patients can receive reasonable compensation and subsistence allowance assistance;

3. Request the National Health and Family Planning Commission to pay attention to this group and include this disease in the scope of government research and treatment, so that the majority of patients can receive timely and effective treatment and have hope in life;

4. Request the National Health and Family Planning Commission to provide approval and support as the competent authority in our application for a public welfare organization, so as to benefit the majority of patients with empty nose syndrome;

5. Request to strengthen the review of medical advertisements to prevent more people from being harmed.

总有一片光明会属于我们，
哪怕是夕阳……
There is always a piece of light that belongs to us,
even if it is the sunset...
空鼻症关爱中心
Empty Nose Syndrome Care Center

We are eagerly awaiting the reply from the National Health and Family Planning Commission! Please include empty nose syndrome among all disease groups treated by the government, and don't let us wait outside the door anymore!

Sincerely

Empty nose syndrome patient group
Contact person: Sun Sulin Tao Jie
Mobile phone: 13764383009 WeChat public account: ENS2016
Email: 3156015201@qq.com

Attachment: Joint signature

1. Sun Sulin, a 47-year-old female living in Shanghai, one of the founders of the public welfare organization for patients with empty nose syndrome. Mobile phone: 13764383009 Email: 3156015201@qq.com

2. Tao Jie, male, 54 years old, living in Shanghai, family member of a patient with empty nose syndrome, one of the founders of the

charity organization for empty nose syndrome

3. Li Zhaoqiang, a 23-year-old male patient with empty nose syndrome living in Qinhuangdao, Hebei Province

4. Huijian, male, 22 years old, patient with empty nose syndrome living in Dalian City, Liaoning Province

5. Zhou Wenjun, male, 26 years old, patient with empty nose syndrome living in Hanzhong City, Shaanxi Province

6. Jiang Huiying, female, 23 years old, living in Fuyang City, Anhui Province, patient with empty nose syndrome

7. Chen Linyue, female, 47 years old, lives in Jiaozuo City, Henan Province, patient with empty nose syndrome

8. Zhou Jinfeng, a 29 year old female patient with empty nose syndrome living in Chongqing

9. Zhang Xianjian, a 38-year-old male patient with empty nose syndrome living in Haining, Zhejiang

10. Pan Ling, male, 29 years old, living in Bijie City, Guizhou Province, patient with empty nose syndrome

11. Du Jintao, a 33-year-old male living in Feicheng City, Shandong Province, a patient with empty nose syndrome

12. Xu Feng, a 33 year old male living in Wuchuan County, Guizhou Province, is a patient with empty nose syndrome.

13. Zhao Jing, a 39-year-old male living in southern Sichuan Province, is a patient with empty nose syndrome.

14. Zhao Longwei, a 30 year old patient with empty nose syndrome from Shijiazhuang City, Hebei Province

15. Wan Shumei, a 46-year-old female, lives in Weinan City, Shaanxi Province, and suffers from empty nose syndrome.

16. Chen Zhanghao, male, 24 years old, patient with empty nose syndrome in Jiaxing, Zhejiang

17. Cheng Zhicheng, male, 24 years old, patient with empty nose syndrome from Xiangyang City, Hubei Province

18. Zhen Tao, male, 36 years old, from Beiguan, Xi'an City, patient with empty nose syndrome

19. Yu Jiaping, male, 33 years old, currently living in Shenzhen City, Guangdong Province, patient with empty nose syndrome

20. Chen Yu, female, 53 years old, patient with empty nose syndrome in Guangshui City, Hubei Province

21. Peng Likang, male, 26 years old, patient with empty nose syndrome in Huizhou City, Guangdong Province

22. Male Li Yiliang, 23 years old, patient with empty nose syndrome in Yancheng City, Jiangsu Province

23. Deng Minggang, male, 31 years old, currently living in Shenzhen City, Guangdong Province, patient with empty nose syndrome

24. Meng Qingqing, female, 26 years old, patient with empty nose syndrome from Linyi City, Shandong Province

25. Niu Meixiang, female, 48 years old, patient with empty nose syndrome in Tongchuan City, Shaanxi Province

26. Xie Chengjin, male, 33 years old, patient with empty nose syndrome in Ganzhou City, Jiangxi Province

27. Pan Feibing, a 42 year old male patient with empty nose syndrome in Taizhou City, Jiangsu Province

28. Chen Yuzhen, a 42-year-old male from Xuzhou, Jiangsu Province, a patient with empty nose syndrome

29. Male Sun Yongzhi, 29 years old, Wuhu City, Anhui Province, patient with empty nose syndrome

30. Female Zhao Birong, 27 years old, patient with empty nose syndrome in Luzhou City, Sichuan

31. Ding Wei, male, 31 years old, patient with empty nose syndrome in Taizhou, Jiangsu Province

32. Zhang Shanhu, male, 44 years old, patient with empty nose syndrome in Xinyang City, Henan Province

33. Male Tang Zhenggang, a patient with empty nose syndrome in Qianxinan Prefecture, Guizhou Province

34. Zhang Lei, male, 29 years old, patient with empty nose syndrome in Xiangyang City, Hubei Province

35. Peng Zhiqiang, male, 48 years old, patient with empty nose syndrome in Weinan City, Shaanxi Province

36. Wu Haibo, male, 36 years old, patient with empty nose syndrome in Changle County, Weifang City, Shandong Province

37. Zhang Lifei, a 32-year-old male patient with empty nose syndrome from Xingtai City, Hebei Province

38. Shi Guanghui, male, 26, patient with empty nose syndrome in Yuxi City, Yunnan Province

39. Ba Yuxue, male, 28 years old, Yongdeng County, Gansu Province, patient with empty nose syndrome

40. Lin Qinggang, male, 24 years old, patient with empty nose syndrome in Anqing, Anhui Province

41. Ling Haibin, male, 30 years old, patient with empty nose syndrome in Xingye County, Guangxi

42. Cai Jinhua, female, 40 years old, patient with empty nose syndrome in Wuhan, Hubei Province

43. Liu Lizui, female, 34 years old, patient with empty nose syndrome in Liaocheng, Shandong Province

44. Dai Hong, female, 40 year old patient with empty nose syndrome in Xiangyang, Hubei Province

45. Xu Hongying female, 20 years old, Shangrao, Jiangxi, patient with empty nose syndrome

46. Wang Liang male, 26 years old, Huaibin County, Xinyang City, Henan Province, patient with empty nose syndrome

47. Zhu Zhongyi, male, 37 years old, Linquan County, Anwei Province, patient with empty nose syndrome

48. Jiang Bingxian, a 39 year old male patient with empty nose syndrome from Yongzhou City, Hunan Province

49. Qin Chengjuan, female, 40 years old, from Mengyin County, Linyi, Shandong Province

50. Wang Hualun, male, 47 years old, patient with empty nose syndrome in Henan Province

51. Xie Zongli, female, 35 years old, patient with empty nose syndrome from Longchang County, Sichuan Province

52. Gui Shangjie, male, 31 years old, currently living in Wuxi City, Jiangsu Province, patient with empty nose syndrome

53. Xie Hao, male, 23 years old, patient with empty nose syndrome in Lu'an City, Anhui Province

54. Liang Liwei, male, 28, patient with empty nose syndrome in Gushi County, Xinyang City, Henan Province

55. Zhou Suwen, female, 66 years old, Panzhihua City, Sichuan Province, patient with empty nose syndrome

56. Dong Guifan, female, 40 years old, Yuzhou, Xuchang, Henan Province, patient with empty nose syndrome

57. Chang Zhigang, 30 year old male, patient from Ulanqab City, Inner Mongolia

58. Xu Biqiang, 22 years old, patient with empty nose syndrome in Chengdu, Sichuan Province

59. Jiang Dong, 22 years old, patient with empty nose syndrome in Wuhu City, Anhui Province

60. Liu Xueqing, female, 33 years old, patient with empty nose syndrome from Ningbo City, Zhejiang Province

61. Han Mei, female, 30 years old, Linyi City, Shandong Province, patient with empty nose syndrome

62. Wang Hua, male, 41 years old, patient with empty nose syndrome in Yantai, Shandong Province

63. Qi Yaoqin, female, 32 years old, Yancheng, Jiangsu Province, patient with empty nose syndrome

64. Wang Jiazhen, male, 34 years old, Pingyin County, Jinan City, Shandong Province, patient with empty nose syndrome

65. Zhang Ze, male, 28 years old, patient with empty nose syndrome from Hanzhong, Shaanxi Province

66. Wang Bo, male, 40 years old, from Chongqing, patient with empty nose syndrome

67. Peng Song, male, 27 years old, patient with empty nose syndrome from Lankao County, Henan Province

68. Lou Tianfu, male, patient with empty nose syndrome from Muling City, Heilongjiang Province

69. Fu Xi, male, 31 years old, Dongchuan District, Kunming City, Yunnan Province, patient with empty nose syndrome

70. Song Xingdong, male, 25 years old, patient with empty nose syndrome from Cang County, Cangzhou City, Hebei Province

71. Tang Chunqiong, female, 31 years old, patient in Panzhou City, Guizhou Province

72. Fan Xiaojie, male, 32 years old, Yongnian County, Handan City, Hebei Province, patient with empty nose syndrome

73. Zhang Xiaochun, male, 28, Jining City, Shandong Province, patient with empty nose syndrome

74. Cheng Shunuo, male, 27 years old, Wuhan City, Hubei Province, patient with empty nose syndrome

75. Sun Xuelei, male, 31, from Junxian County, Henan Province, patient with empty nose syndrome

76. Zhang Xuedong male, 27 year old patient with empty nose syndrome in Ma'anshan, Anhui Province

77. Wang Yimeng, male, 18 years old, family member of a patient with empty nose syndrome in Changchun, Jilin

78. Liu Jinbo, female, 45 years old, patient with empty nose syndrome in Changchun, Jilin

79. Tang Sai, female, 31 years old, Hunan, patient

80. Male Sun Xiaoyang, 28 years old, currently living in Shenzhen, patient with empty nose syndrome

81. Jiang Bin, male, Han nationality, 34 years old, patient with empty nose syndrome in Pengxi County, Sichuan Province

82. Li Dongfei, male, 27 years old, living in Henan Province, patient with empty nose syndrome

83. Xu Long male, Han nationality, 21 years old, patient with empty nose syndrome in Tongxiang City, Zhejiang Province

84. Wang Yongji, male, Han nationality, 29 years old, patient with empty nose syndrome in Xinyang City, Henan Province

85. Huang Chunquan, female, Zhuang ethnic group, 45 years old, Yizhou, Guangxi, patient with empty nose syndrome

86. Fu Zhongxing, female, Han nationality, 70 years old, patient in Shanghai

87. Zhang Ruinan, 27 years old, patient with empty nose syndrome in Ruian City, Zhejiang Province

88. Yu Qiusong, 33 years old, male, from Hechuan, Chongqing, patient with empty nose syndrome

89. Shang Jianping, male, 30, from Xingtai, Hebei Province, patient with empty nose syndrome

90. Wang Zhixing, male, patient with empty nose syndrome in Nanchang City, Jiangxi Province

91. Chen Weinan, Han nationality, 34 years old, patient with empty nose syndrome in Xintai City, Shandong Province

92. Zhu Jing, female, Han nationality, 32 years old, patient with empty nose syndrome in Enshi, Hubei Province

93. Zhou Yuannan, Han nationality, 27 year old patient with empty nose syndrome in Suzhou City, Anhui Province

94. Li Yonghui, male, Han nationality, 28 years old, patient with empty nose syndrome in Zaozhuang City, Shandong Province

95. Li Liang, male, Han nationality, 39 years old, patient with empty nose syndrome in Linquan County, Anhui Province

96. Zhang Hong, female, 28 years old, Luoyang, Henan Province, patient with empty nose syndrome

97. Yu Linan, a 54 year old patient with empty nose syndrome from Yichang City, Hubei Province

98. Ye Meinian, female, 25 years old, patient in Guangzhou City, Guangdong Province

99. Zheng Zewei, male, Han nationality, 24 years old, patient with empty nose syndrome in Lanzhou City, Gansu Province

100. Shi Yue, male, Han nationality, 23 years old, patient with empty nose syndrome in Gansu Province

101. Chen Yuanqiang, male, Han nationality, 30 years old, Guangzhou City, patient with empty nose syndrome

102. Wang Pengcheng, male, Han nationality, 24 years old, patient with empty nose syndrome in Zhanjiang City, Guangdong Province

103. Lu Yan, female, Han nationality, 36 years old, patient with empty nose syndrome in Hefei, Anhui Province

104. Zhang Yuzhuang, male, Han nationality, 24 years old, patient with empty nose syndrome in Xuzhou City, Jiangsu Province

105. Zhang Xingang, male, 35 years old, patient with empty nose syndrome in Cangzhou, Hebei Province

106. Li Youchang, male, patient with empty nose syndrome in Zhanjiang, Guangdong

107. Hu Zelin, male, patient with empty nose syndrome in Xiamen, Fujian

108. Li Zhicui, male, Han nationality, Qingyuan, Guangdong, patient with empty nose syndrome

109. Wang Fujun, male, Han nationality, Baiyin, Gansu, patient with empty nose syndrome

110. Li Yang, male, Han nationality, Xuzhou, Jiangsu, patient with empty nose syndrome

111. Huang Zhiming, male, Han nationality, 29 years old, patient with empty nose syndrome

112. Nie Xubing, male, Han nationality, Hailar, Inner Mongolia, patient with empty nose syndrome

113. Fu Songrong, female, Han nationality, 43 years old, living in Luoyang, Henan, patient with empty nose syndrome

114. Sun Yanzhou, male, Han nationality, living in Shandong Province, patient with empty nose syndrome

115. Liu Fangbin, male, Han nationality, Chengdu, Sichuan, patient with empty nose syndrome

116. Liu Jianping, male, Han nationality, Guilin, Guangxi, patient with empty nose syndrome

117. Ma He, male, Han nationality, Zhengzhou, Henan, patient with empty nose syndrome

118. Qiu Li, female, Han nationality, Ningbo, Zhejiang, patient with empty nose syndrome

119. Tian Wenbo, male, Han nationality, patient with empty nose syndrome in Xi’an, Shaanxi Province

120. Wang Bin, male, Han nationality, Shaoyang, Hunan, patient with empty nose syndrome

121. Liang Zilin, male, Han nationality, Zhanjiang, Guangdong, patient with empty nose syndrome

122. Han Yanhong, female, Han nationality, patient with empty nose syndrome in Xining, Qinghai

123. Shi Yunchao, male, Han nationality, Ningbo, Zhejiang, patient with empty nose syndrome

124. Gan Lichang, male, Han nationality, Guiyang, Guizhou, patient with empty nose syndrome

125. Xue Shuna, female, Han nationality, Quanzhou, Fujian, patient with empty nose syndrome

126. Wang Chenhao, male, Han nationality, Baoding, Hebei, patient with empty nose syndrome

127. Liu Jinhui, male, Han nationality, Shaoguan, Guangdong, patient with empty nose syndrome

128. Wang Yan, male, Han nationality, Shanghai, patient with empty nose syndrome

129. Zheng Qibing, male, Han nationality, Zhangzhou, Fujian, patient with empty nose syndrome

130. Ma Yuanjia, male, Han nationality, Nanyang, Henan Province, patient with empty nose syndrome

131. Liao Pan, male, Han nationality, from Chengdu, patient with empty nose syndrome

132. Li Shuya, female, Han nationality, Suzhou, Jiangsu, patient with empty nose syndrome

133. Hu Mengxia, female, Han nationality, Wuhan, Hubei, patient with empty nose syndrome

134. Chang Hailong, male, Han nationality, Xi’an, Shaanxi, patient with empty nose syndrome

135. Ling Haibin, male, Han nationality, Guangzhou, Guangdong, patient with empty nose syndrome

136. Zhang Binan, male, Han nationality, Xianyang, Shaanxi, patient with empty nose syndrome

137. Du Lin, male, Han nationality, Chongqing City, patient with empty nose syndrome

138. Shen Zhenhua, male, Han nationality, Suzhou, Jiangsu, patient with empty nose syndrome

139. Fan Lijie, male, Han nationality, Beijing, patient with empty nose syndrome

140. Xie Yuesheng, male, Han nationality, Chongzuo, Guangxi, patient with empty nose syndrome

141. Liu Jinxin, male, Han nationality, 28 years old, from Weifang, Shandong, patient with empty nose syndrome

142. Hou Quanquan, male, Han nationality, Dongguan, Guangdong, patient with empty nose syndrome

143. Yang Jun, male, Han nationality, Nanyang, Henan, patient with empty nose syndrome

144. Jiang Xiangming, male, Han nationality, 47 years old, Nanjing, Jiangsu, patient with empty nose syndrome

145. Hu Yingbin, male, Han nationality, Jingmen, Hubei Province, patient with empty nose syndrome

146. Liu Jiangnan, Han nationality, Taizhou, Zhejiang, patient with empty nose syndrome

147. Yu Jinglin, male, Han nationality, 46 years old, Nanning, Guangxi, patient with empty nose syndrome

148. Gu Shuo, male, Han nationality, 29 years old, Yixing, Jiangsu Province, patient with empty nose syndrome

149. Ma Xiaohua, male, Han nationality, 36 years old, Guyuan City, Ningxia, patient with empty nose syndrome

150. Li Chao, male, Han nationality, 30 years old, Lianyungang, Jiangsu, patient with empty nose syndrome

151. Wang Yong, male, Han nationality, 31 years old, Hengyang City, Hunan, patient with empty nose syndrome

152. Nong Jihua, male, Han nationality, 29 years old, patient with empty nose syndrome in Shenzhen, Guangdong

153. Li Xinshuo, male, Han nationality, 33 years old, patient with empty nose syndrome in Puyang, Henan

154. Guan Chao, male, Han nationality, 19 years old, patient with empty nose syndrome in Hanzhong City, Shaanxi Province

155. Fu Yun, male, Han nationality, 37 years old, a patient with empty nose syndrome from Chongqing

156. Wang Jihe, male, Han nationality, 42 years old, Heyuan City, Guangdong Province, patient with empty nose syndrome

157. Zhang Hong, male, Han nationality, patient with empty nose syndrome in Xiamen, Fujian

158. Xu Xiangxiao, male, Han nationality, 32 years old, Sanming City, Fujian Province, patient with empty nose syndrome

159. Zhou Ming, male, Han nationality, 28 years old, Huaibei City, Anhui Province, patient with empty nose syndrome

160. Zheng Youyuan, female, 67 years old, Hubei Province, family member of a patient with empty nose syndrome

161. Gong Yonghuai, male, Han nationality, 28 years old, Laohekou City, Hubei Province, patient with empty nose syndrome

162. Zhang Xinyang, male, Han nationality, 27 years old, Chuzhou City, Anhui Province, patient with empty nose syndrome

163. Liang Songhong, male, 51 years old, currently living in Weinan City, Shaanxi Province, family member of a patient with empty nose syndrome

164. Zhang Yin, male, 25 years old, Chongqing City, patient with empty nose syndrome

165. Liu Wentao (committed suicide due to unbearable torture), male, 23 years old, from Dalian, patient with empty nose syndrome

166. Di Yuemei (committed suicide due to unbearable torture), female, 54 years old, from Beijing, patient with empty nose syndrome

34 comments default up to date

Junjun
I hope there will be a medical breakthrough
2018-05-08 reply

Tao Juan
We are waiting in pain, please give us a little hope!
2021-12-10 reply

empty
How to contact
2023-12-30 reply

Tao Juan
I also have empty nose syndrome! A hellish life. Dry and painful breathing! My nose felt dry and uncomfortable all night and I couldn't sleep! Life is worse than death!
2021-11-09 reply

forest wood
Really, there are some things that you have to be cautious about
2018-08-11 reply

Zhihu user 16UlY8
I have empty nose syndrome
2018-07-03 reply

The armor is still there
I had a second surgery when I was a kid, it was really dangerous now that I think about it!
2018-03-22 reply

moldy boyfriend
how do you feel now
2018-07-26 reply

Charlie author
Empty nose syndrome can be treated. I have updated the treatment methods on Lilac Garden.
2020-04-07 · Hot comments reply

Da Luo staff
What is Lilac Garden software?

2023-12-05 reply

Bobo
come on
2018-03-23 reply

Bikachu
come on!
2018-03-11 reply

empty
I also have the same disease, how can I contact you?
2023-12-30 reply

empty
I also have the same disease, how can I contact you?
2023-12-30 reply

jhlytc
I am also a patient with empty nose syndrome after surgery. I am suffering every day. I hope to join Sun Shulin WeChat to gain a little strength and enhance my confidence.
2023-05-20 reply

Zhang Xiaofei Feifeili
Zhang Erhai, a patient with empty nose syndrome, whose mobile phone number is 18749871246, committed suicide eight times at Henan Provincial People's Hospital.
2023-03-19 reply

empty ▸ **Charlie**
How to relieve it?
2023-12-30 reply

Charlie author
I don’ t understand, there are so many ways to relieve the pain, so why do some people still want to commit suicide?
2023-08-03 reply

Don't want to be smart
Hello, what are the more promising treatments now? We can't forget to fill in something like this which gets darker and darker as it gets drawn.
2019-12-20 reply

Zhihu user I1z8IC ▸ **Charlie**
1

2023-06-25 reply like

Charlie author

zhuanlan.zhihu.com/p/10

Just follow this idea

2020-01-14 reply

common

Isn't anyone paying attention?

2019-10-12 reply

Jiangxia Jinse

Come on, it hurts to see it

2019-05-17 reply

silently

More than 80% of people will experience discomfort after turbinate surgery, and more than 20% will develop empty nose syndrome. There are about 300 million rhinitis patients in our country. According to theoretical calculations, the number of patients with empty nose syndrome in our country is about 6 million. The question arises: Do all 300 million people with rhinitis choose surgery?

2019-04-27 reply

wxya ▸ **Wenfeng**

The 20% probability of developing empty nose syndrome is a bit exaggerated. If it is true that 20% will develop empty nose syndrome, then many doctors will naturally report the shortcomings of this surgery to the society through papers. Even if you say that Chinese doctors are unwilling to speak out in this environment, it will definitely be the case. There are many foreign experts discussing this issue. But the problem is that, with the support of the so-called 20% probability, the disease "empty nose syndrome" has not been recognized by the medical community. Furthermore, if there is a 20% probability of getting empty nose syndrome, then the hospital will not introduce this technology in the first place. After all, which hospital is not afraid of medical trouble? A low-temperature plasma ablation device costs several hundred thousand yuan. A large hospital conservatively estimates to perform 20 ablation surgeries every day, 140 surgeries a week, resulting in 28 patients with empty nose syndrome. The otolaryngology department of the hospital is estimated to even have curtains. It's all been torn apart, will it still look like it's calm now? In fact, the correct answer to this problem should be that 19.99% of patients undergoing turbinate surgery in Putian Hospital have the risk of empty nose syndrome, while the risk in regular tertiary hospitals is 0.001%. If it is true that there is a 20% risk in just doing surgery as these rumors say, then no one in the country would dare to be an otolaryngologist, because as long as you learn otolaryngology, you must learn rhinal surgery. It is impossible for an otolaryngologist to do it A doctor will never perform turbinate surgery on a

patient for the rest of his life. So, it can be said that these rumors have delayed many patients who could have solved their nasal ventilation problems through surgery, and inserted a knife of fear into the hearts of many patients who are facing surgery.

2021-02-18 reply

Wenfeng

One-tenth of the cost is surgery, so isn' t 20% of 30 million equivalent to 6 million?

2019-10-25 reply

Versatile

Pay attention to the follow-up

2019-02-01 reply

bus sword

come on

2018-08-13 reply

zzk109

Why do I feel that all diseases can be related to empty nose syndrome? This is really the first time I have heard that the lungs can also produce blood. It is better to read the literature quickly, otherwise I will be left behind again.

2018-06-05 reply

fire spirit ly

come on!

2018-05-29 reply

Li Zhaoqiang

Copyright belongs to the author, is it copied?

2018-05-24 reply

Respiratory health and growth

The country cannot abandon these innocent people and families

2022-06-13 reply

Well-off for all

Please let the country pay attention to these unfortunate people. We patients with empty nose syndrome are in too much pain.

2022-06-03 reply

little woman

I also have syrinx syndrome, and I was treated by Kamata Shiko for the surgery. Now I realize that I regret it too late. It' s really because I have too many post-operative symptoms.

空鼻症患者及社会各界爱心人士致国家卫计委的一封联名公开信

Original 孙素林 空鼻症关爱中心 2018-03-09 09:03

联名背景：

自上世纪九十年代以来，鼻炎手术大量普及，且在2010年前后达到高峰，但却造成了大量的空鼻症患者。因为不堪忍受非人的折磨，加上失去劳动能力，全世界都没有治疗方法，让空鼻症患者彻底失去了生活的信心和希望，患者猝死和自杀事件时有发生，2016年北京画家诗人狄月媚、大连小伙刘文涛、新疆女孩张瑞先后跳楼自杀，2013年前后，山西运城18岁高中女孩和襄阳30年轻妈妈在鼻炎手术后在睡觉时猝死……,这些事件的发生强烈的震撼着每一位空鼻症患者，我们必须要向社会各界发出我们的求救声，让社会各界、各级政府能够看到空鼻症患者的生存症状，给在疾病煎熬中苦苦等待的每个空鼻症患者家庭一份希望、一丝曙光。我们想要好好活下来！我们需要研究治疗方法！

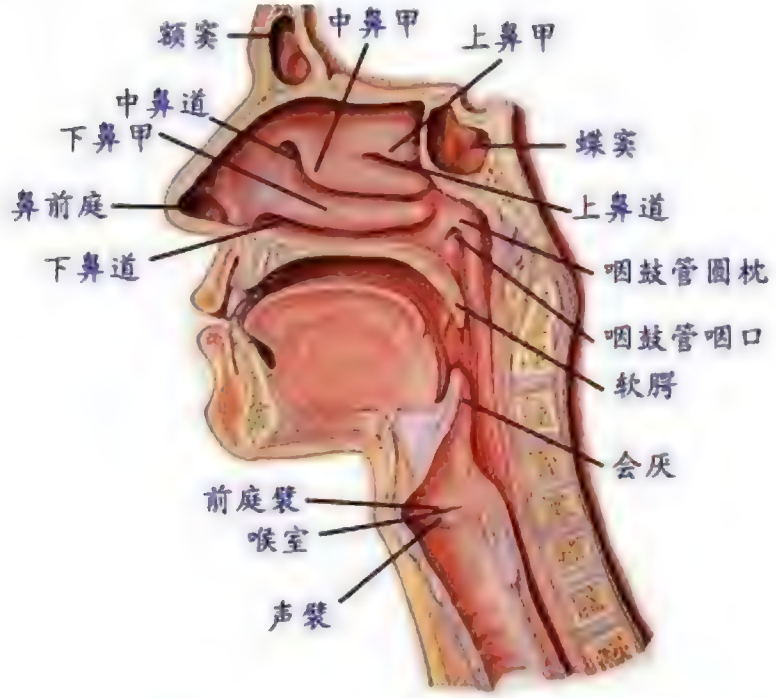
下面是空鼻症患者共同联名致国家卫计委的一封公开信，希望社会各界人士加入到我们的爱心联名中来，伸出您的援手，您的一个留言、一个联名就会让空鼻症患者离希望更近一步！

尊敬的国家卫计委：

您好！我们是空鼻症患者群体，由患者和患者家属自发组成，我们的宗旨是为患者提供帮扶救助，心理疏导和情感关怀，让大家能够互助关爱、充满正能量、树立战胜疾病的信心、和谐医患关系。同时为大众科普空鼻症知识和预防措施。我们尽最大可能为空鼻症患者寻找研究治疗办法，争取让患友有病可医，得到社会广泛认可和支持,促进社会和谐进步。

空鼻症最早由美国医生提出，近几年才逐渐被国人所知晓，但还没引起医疗界重视和认可。

空鼻症： 既空鼻症候群或空鼻综合征，简称空鼻症，英语：Empty Nose Syndrome，缩写：ENS。空鼻症是一种医源性慢性衰竭性疾病。这个病主要是后天获得性疾病，主要由外部原因导致，主要由鼻甲手术、腐蚀、外伤等造成，如：鼻甲切除、等离子消融、药物腐蚀等手术,及车祸、烧伤、化学品腐蚀、美容等外力伤害导致的呼吸功能障碍及一系列全身并发症。是一种后果严重、不可逆的、持续恶化、无法医治的疾病，是世界性难题。



鼻腔、口腔、咽和喉的正中

空鼻症有哪些病症？

根据国内外耳鼻喉科专家描述及患者自身症状描述收集：

大部分空鼻症患者多有鼻干、鼻疼、通气大、通气凉、鼻腔干燥结痂、黏膜发白发干、鼻甲萎缩、鼻腔宽大、咳嗽、鼻涕倒流、流鼻涕、粘稠鼻腔分泌物、咽干涩疼、眼干涩视物模糊、脱发、耳阻塞感、头疼、头晕无力、疲劳、困倦乏力、记忆力下降、精力不足、劳动能力下降、注意力无法集中、抑郁挫折或不安或易怒、睡眠困难等全身病症状。

严重的患者甚至产生呼吸困难、窒息、缺氧、胸闷、心慌、气短、头晕无力、腰酸背痛、浑身疼痛、肺纹理增粗、肺功能严重下降、肺部结节、慢性阻塞性肺病、心率失常、骨质疏松、血小板下降、血尿、肠胃不适、肝部疼痛、内分泌失调、高血压、高血糖、高血脂、全身多器官功能严重下降、全身器官慢性衰竭等严重并发症，患者如同在炼狱里煎熬、生不如死并丧失劳动力，生活质量很差、时刻有生命危险，有些患者甚至发生猝死，更有一些患者受不了这种非人的折磨而绝望自杀。

空鼻症发病机制是什么？

（1）． 鼻甲有感知、加温、加湿、调节、防御、清洁、免疫、共鸣、神经反射等功能。鼻甲被切除后，其包含的海绵体、血管、粘膜及神经被相应切除或消融，鼻甲及粘膜不能再充盈血液导致血供不足、黏膜面积减少、鼻腔粘膜感受器成比例下降、鼻阻力下降、鼻腔调节功能下降、腺体分泌功能破坏等共同参与致病。（引用自医学资料文献）

（2）． 鼻甲被认为是神经生长因子的一个来源，鼻腔黏膜有丰富的腺体及感受器，鼻甲黏膜遭到破坏后腺体及感受器的数量下降，加上血供不足、神经生长因子减少，神经再生和愈合困难，鼻甲及黏膜便会逐步萎缩，对气流感觉和传输功能下降，鼻肺、鼻心等反射功能下降，心肺的血气氧和能力发生障碍、严重者导致严重的高铁血红蛋白症，即MetHb。因为MetHb不能携氧和可逆性地释放氧。原来可与氧结合的铁离子部位都失去了电子，与羟基或氯化物牢固地结合。MetHb的主要临床表现为缺氧和发绀、呼吸困难、头晕为常见临床表现，严重者可导致死亡。这也说明了为什么很多空鼻症患者有窒息、缺氧、呼吸困难、头晕无力等病症。（引用自医学资料文献）

（3）． 鼻阻力整个呼吸道阻力50%-80%来源于鼻腔阻力。适宜的鼻腔阻力有助于维持周围支气管开放和肺泡扩张，进而保证气体交换顺利进行、维持胸腔负压以利于体循环和肺循环的静脉回流和充足的静脉回心血量。呼气时正常的鼻腔阻力可帮助维持肺容积，且可能间接影响动脉氧合情况。鼻甲切除术或消融术后，鼻腔阻力的下降，气体、黏膜表面的压强差随之减小，致使鼻肺支气管反射的功能异常，呼吸道及肺功能受到影响，并致肺功能恶化，患者出现胸闷气短、呼吸困难，甚至窒息感。（引用自医学资料文献）

（4）． 最新的科学研究表明，鼻子和肺共同组成人体的呼吸系统，鼻子是呼吸的源头很延伸，源头受损必然影响肺功能。肺部不仅用于呼吸，也是参与血液生成的关键组成部分。肺是血小板生物合成的场所，是造血祖细胞的贮库，肺部负责生产超过一半的血小板。（见-《肺的新功能-造血》）

空鼻症患者有多少人？

据国内外专家提出：鼻甲手术后80%以上的人会出现不适，约20%以上的会发展为空鼻症。我国约3亿鼻炎患者，据理论推算，我国空鼻症患者人数约为600万左右，这个数量远远超过了欧美国家患者的总和，而且我国患者的患病程度远远比其他国家严重，很多患者猝死或无法忍受折磨而自杀。

空鼻症患者的生存状况：

空鼻症患者的生存状况可以用地狱来形容一点不过，我们中的很多人原本都是健康人，却因为缺失了很小一点的鼻甲从此改写人生，掉进黑暗的地狱。呼-吸这个再

平常不过的生理运动对我们来说已经变成了奢望，几乎每个人都有呼吸障碍，我们虽然外表无损，身体各器官却无法正常运行，每个人都有一身的毛病，全身器官亮起红灯。

因为空鼻症，还在上学的孩子不能再正常学习，原本美满的家庭夫妻离异、家庭支离破碎，家庭积蓄化为乌有，蒸蒸日上的事业毁于一旦，上无法赡养父母下无力抚养儿女、卖房卖地都看不好这个恐惧的疾病。因为空鼻症，我们原本健壮的身躯轰然倒塌、不得不躺在病榻之上苟延残喘，呼吸都成问题，原来生龙活虎现在却手无缚鸡之力，身体瀛弱的不及80多岁的老人，变成了被照顾的对象。

因为空鼻症，我们一人得病拖垮整个家族，原本是家庭的顶梁柱和骄傲、公司的业务骨干，现在却完全丧失劳动能力、干不了任何事、被单位辞退，失去了挣钱能力，成了家庭的负担和拖累，我们无脸再见朋友同事，与世隔绝，郁郁寡欢，整个世界只剩下鼻子。

医疗界、社会各界对空鼻症的认知有限：

因为空鼻症目前尚未进入疾病目录，疾病信息不够透明公开，教材也没及时更新，很多耳鼻喉医生都不知道空鼻症这个疾病，很多权威的专家对空鼻症也知之甚少，甚至医学生、医生、医学院教授、还有耳鼻喉科医生自己都成了鼻炎手术的受害者，做了鼻甲切除，成了空鼻症大军的一员，更不要说没有医学常识的普通老百姓了。因为空鼻症的疾病信息不透明，患者到医院就诊造成的误诊率漏诊率达到90%以上，现在还有大部分的鼻炎手术患者依然蒙在鼓里，即便术后深受并发症折磨却不知道自己就是空鼻症患者。空鼻症患者中有人甚至被误诊达40年，直到他的儿女在网上看到我们做的空鼻症科普才知道严重困扰自己父亲多年的病症原来是空鼻症，可这个患者已是垂暮年龄的老翁，几乎被空鼻症困扰半个世纪，可这么多年来在多家医院就诊却一直不知道问题出在哪里。还有一个湖北宜昌的空鼻症患者多年来一直被认为是肺出了问题，硬生生吃了多年的呼吸科药物也不见好转，甚至还恶化了，直到看到我们的科普才搞明白。也有少数医生知道空鼻症这个疾病，可迫于各种压力不敢告知患者真相，他们也很困惑，因为以前这个鼻甲等离子消融术曾风靡一时，很多医院的耳鼻喉科不惜花大价钱引进这种设备和技术，但没想到国外先进技术存在这么大缺陷，你让这些医生怎么面对他（她）的患者？怎么解释？这确实是个难题！作为患者我们很理解，毕竟现行的医疗科技对人体的认知还远远不够，医疗技术的应用也是在不断的探索实践中推陈出新，日新月异，一项新技术在运用中出现了瑕疵也很正常，但出现偏差请及时修正，让我们能有病可医、能够治疗缓解。毕竟空鼻症有这么大的群体在那儿，是不容忽视的社会问题。

由于现有的科技手段局限及科室诊疗范围限制，大多数空鼻症患者在医院就诊时很难查出鼻甲损伤的问题，但事实上空鼻症患者鼻甲损伤后更多是导致其他器官出现

问题，比如：肺功能、血液检查、尿液检查、心脏、血压、血糖等，但由于是鼻子引起的问题，大多数医生很难把鼻子的问题和身体其他器官的病症联系起来，由此造成了空鼻症患者的诊断只能单纯依靠对鼻甲的检查，而不是同其他器官联系起来综合诊断检查，所以也造成了鉴定难、定残难。很多医生由此觉得空鼻症患者是心里出了问题，得了抑郁症，家人由开始的同情逐渐变为愤怒和不理解，他们觉得既然医生都检查说没问题，肯定是自己家里人在作、在无理取闹。有的家庭甚至把空鼻症患者强行送到精神病医院接受治疗。

因为现行的教材课本里对空鼻症的描述和诊断几乎是一片空白，空鼻症患者进入诉讼时无法做鉴定而得不到赔偿，法院的驳回理由是无法做伤残鉴定，鉴定机构退鉴的理由是没有对应的伤残鉴定标准。因为无法定残，很多失去劳动的空鼻症患者拿不到残疾证，办不了低保和救助，整个群体陷入孤立无援的境地。当其他疾病群体在为治病的药纳入医保而呼吁时，而我们却连个疾病名称都没有，更不要谈研究治疗了。因为这个疾病没有纳入疾病目录，所以没有任何机构愿意研究，我们成了无药可救的孤儿，我们眼睁睁的看着空鼻症患友们在深渊里挣扎、在生不如死的炼狱里煎熬却束手无策。因为看不到治疗和生活的希望，很多患者绝望自杀或走极端。

因为鼻炎手术来钱快，获利简单，加之患者受害无法鉴定和得到赔偿，很多民营医院很好的利用了这一法律灰色地带，在网络大肆宣传拉客，把老百姓指引到错误的医院接受这种错误的手术，被害者中大部分都是青少年。而这些人本来风华正茂、年富力强，正是干事业的好年龄，却因为空鼻症而毁了一生，由创造社会价值和财富的中坚力量变成了社会的负担，变成了一大社会问题。很多民营医院当时虽然得到了几千元的蝇头小利，却为整个社会带来了无法估量的损失和负担，造成了极其严重的社会问题。

我们注册空鼻症公益组织面临的困境：

为了能让空鼻症能纳入疾病目录，为了研究治疗空鼻症，为了帮扶救助这个灾难的群体，为了研究治疗空鼻症，孙素林和陶杰甚至不惜廉价卖掉上海唯一的房子。四年来他们一直在奔走呼吁，为了更好的运行这个组织和提高公信力，我们一直在为注册成立为正式的公益组织而努力，从北京到广东到深圳到湖北到广州到上海……，但注册之路却充满了艰辛和挫败感，无数次的被拒之门外，回复是没有业务主管单位卫计委批准，我们也找了相关地方的卫计委，回答是不属于他们管，我们真切的感到迷茫和无助，很多时候呆坐在各级民政局大厅或卫计委大门前步履蹒跚，不知道该走向哪里？

作为泱泱大国的患者，我们时常感到汗颜，现在欧美国家早就注册成立了空鼻症患者公益组织，我们却连个疾病名称都没有。每次面对国外患者及公益组织的质疑和追问，我们只有苦笑或避而不谈。因为没有一个正式的公益组织，我们每次出门和其他机构及个人交流，总是被怀疑，我们到底代表谁？我们又能代表谁？我们自己是谁？因为没有组织，我们很难募集到善款；因为没有组织，我们做事说话没有公信力；因为没有组织，我们的活动很难开展；因为没有组织，我们不被认可和关

注；.....太多太多的艰难困境，希望作为主管部门的卫计委能批准我们成立空鼻症患者组织，希望民政部能放开胸怀接纳我们。

空鼻症患者的心声和期盼：

为了减轻社会负担，同时也为了数百万空鼻症能重燃生活的希望和信心，为了社会和谐安宁，为了我们能重回社会、重回工作岗位、为了无数家庭的健康幸福，我们呼吁社会各界引起重视，正视空鼻症这个问题，中国有3亿鼻炎患者，谁又能保证他们不会成为下一个空鼻症呢？ 在此含泪再次请求国家卫计委能倾听我们的心声，伸出援手，能重视我们的诉求，让空鼻症患者有个出路和希望：

1、 请求国家卫计委能把“空鼻症”纳入疾病目录，让约600万患者得到确诊。

2、 请求国家卫计委根据致残程度轻重对空鼻症给出伤残等级和鉴定标准，让鉴定机构和司法机构有个明确依据，让患者能得到合理赔偿和低保救助；

3、 请求国家卫计委能重视这个群体，能把此病纳入政府研究治疗的范围，让广大患者能得到及时有效的治疗，生活有个希望；

4、 请求国家卫计委能在我们申请公益组织过程中作为主管单位给与批复和支持，造福广大空鼻症患者；

5、 请求加强医疗广告审查力度，避免更多人受害。

我们急切期待国家卫计委的回复！恳求在政府治疗的所有疾病群体中能把空鼻症也包括进来，不要让我们再在门外等待！

此致

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29. 孙永智 男，29岁 安徽芜湖市 空鼻症患者
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32. 张善虎 男，44岁 河南省信阳市 空鼻症患者
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76. 张学东 男 27岁 安徽马鞍山 空鼻症患者
77. 王艺蒙 男，18岁，吉林长春 空鼻症患者家属
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90. 王志兴 男，江西省南昌市 空鼻症患者
91. 陈瀛 男，汉族，34岁 山东省新泰市 空鼻症患者
92. 朱婧 女，汉族， 32岁，湖北省恩施 空鼻症患者
93. 周袁 男，汉族，27岁 安徽省宿州市 空鼻症患者
94. 李永辉 男，汉族，28岁，山东省枣庄市 空鼻症患者
95. 李良 男， 汉族，39岁 安徽省临泉县 空鼻症患者
96. 张弘 女，28岁 河南省洛阳，空鼻症患者
97. 余力 男，54岁 湖北省宜昌市 空鼻症患者
98. 叶美年 女，25岁，广东广州市，患者
99. 郑泽伟 男，汉族，24岁，甘肃省兰州市 空鼻症患者
100. 石越 男，汉族，23岁， 甘肃省 空鼻症患者
101. 陈远强 男，汉族，30岁 广州市 空鼻症患者
102. 王鹏程 男，汉族，24岁 广东省湛江市 空鼻症患者
103. 吕艳 女，汉族，36岁， 安徽省合肥 空鼻症患者
104. 张玉壮 男，汉族，24岁，江苏省徐州市 空鼻症患者
105. 张新港 男，35岁，河北沧州空鼻症患者
106. 李有昌 男，广东湛江 空鼻症患者
107. 胡泽林 男，福建厦门 空鼻症患者

108. 李志崔 男，汉族，广东清远，空鼻症患者
109. 王福君 男，汉族，甘肃白银，空鼻症患者
110. 李阳 男，汉族，江苏徐州， 空鼻症患者
111. 黄志明 男，汉族，29岁，空鼻症患者
112. 聂许兵 男，汉族，内蒙古海拉尔，空鼻症患者
113. 付嵩荣 女，汉族，43岁，居住河南洛阳，空鼻症患者
114. 孙延洲 男，汉族，居住山东省，空鼻症患者
115. 刘方斌 男，汉族，四川成都，空鼻症患者
116. 刘建平 男，汉族，广西桂林，空鼻症患者
117. 马贺 男，汉族，河南郑州，空鼻症患者
118. 裘丽 女，汉族，浙江宁波，空鼻症患者
119. 田文博 男，汉族，陕西西安 空鼻症患者
120. 王斌 男，汉族，湖南邵阳， 空鼻症患者
121. 梁子林 男，汉族，广东湛江，空鼻症患者
122. 韩燕红 女，汉族，青海西宁 空鼻症患者
123. 史云超 男，汉族，浙江宁波，空鼻症患者
124. 甘力畅 男，汉族，贵州贵阳，空鼻症患者
125. 薛淑娜 女，汉族，福建泉州，空鼻症患者
126. 王琛浩 男，汉族，河北保定，空鼻症患者
127. 刘锦辉 男，汉族，广东韶关，空鼻症患者
128. 王颜 男，汉族，上海市，空鼻症患者
129. 郑奇兵 男，汉族，福建漳州，空鼻症患者
130. 马元甲 男，汉族，河南省南阳,空鼻症患者
131. 廖攀 男，汉族，成都人，空鼻症患者
132. 李舒亚 女，汉族，江苏苏州，空鼻症患者
133. 胡梦霞 女，汉族，湖北武汉，空鼻症患者
134. 常海龙 男，汉族，陕西西安，空鼻症患者
135. 凌海斌 男，汉族，广东广州，空鼻症患者
136. 张彬安 男，汉族，陕西咸阳，空鼻症患者
137. 杜林 男，汉族，重庆市，空鼻症患者
138. 沈振华 男，汉族，江苏苏州，空鼻症患者
139. 范利杰 男，汉族，北京市，空鼻症患者
140. 谢月生 男，汉族，广西崇左，空鼻症患者
141. 刘金鑫 男，汉族，28岁，山东潍坊人,空鼻症患者

142. 侯权权　男，汉族，广东东莞，空鼻症患者
143. 杨俊　男，汉族，河南南阳，空鼻症患者
144. 姜向明 男，汉族，47岁，江苏南京，空鼻症患者
145. 胡应斌　男，汉族，湖北荆门，空鼻症患者
146. 刘江 男，汉族，浙江台州，空鼻症患者
147. 玉精林　男，汉族，46岁，广西南宁，空鼻症患者
148. 顾硕　男，汉族，29岁，江苏省宜兴，空鼻症患者
149. 马小花　男，汉族，36岁，宁夏固原市，空鼻症患者
150. 李超　男，汉族，30岁，江苏连云港，空鼻症患者
151. 王勇　男，汉族，31岁，湖南衡阳市，空鼻症患者
152. 农济华　男，汉族，29岁，广东深圳 空鼻症患者
153. 李昕朔　男，汉族，33岁，河南濮阳 空鼻症患者
154. 关超　男，汉族，19岁，陕西省汉中市 空鼻症患者
155. 傅云　男，汉族，37岁，重庆人 空鼻症患者
156. 王继和　男，汉族，42岁，广东省河源市，空鼻症患者
157. 张红　男，汉族，福建厦门 空鼻症患者
158. 徐向晓　男，汉族，32岁，福建省三明市，空鼻症患者
159. 周明　男，汉族，28岁，安徽省淮北市，空鼻症患者
160. 郑有元　女，67岁，湖北省，空鼻症患者家属
161. 龚永怀　男，汉族，28岁，湖北省老河口市，空鼻症患者
162. 张新阳　男，汉族，27岁，安徽省滁州市，空鼻症患者
163. 梁宋宏，男，51岁，现居陕西省渭南市，空鼻症患者家属
164. 张印，男，25岁，重庆市，空鼻症患者
165. 刘文涛（不堪折磨自杀）男，23岁，大连人，空鼻症患者
166. 狄月媚（不堪折磨自杀）女，54岁，北京人，空鼻症患者

最新

君君
希望医疗上有所突破
2018-05-08 回复

陶娟
我们痛苦熬着等着，请给我们一点希望吧！
2021-12-10 回复

空空
怎么联系
2023-12-30 回复

陶娟
我也是空鼻症！地狱一般生活。呼吸干痛难受！整晚鼻子干难受像睡不着！生不如死！
2021-11-09 回复

森林木
真的，有些事情必须要谨慎谨慎再谨慎
2018-08-11 回复

知乎用户16UlY8
我就是空鼻症
2018-07-03 回复

铁甲依然在
我小时候做过二次手术，现在想想真是险！
2018-03-22 回复

发霉的男友
现在什么感觉
2018-07-26 回复

查理 作者
空鼻症已经可以治疗了，治疗方法我更新在丁香园上面了
2020-04-07 · 热评 回复

大罗法杖
丁香园是啥呀 软件吗
2023-12-05 回复

波波
加油
2018-03-23 回复

比卡诸
加油!
2018-03-11 回复

空空
我也是这个病，怎么联系你。
2023-12-30 回复

空空
我也是这个病，怎么联系你。
2023-12-30 回复

jhlytc
我也是术后的空鼻症患者，每天都煎熬中度过，希望加入孙树林微信，增加一点点力量，也为自己增强信心
2023-05-20 回复

张小飞飞飞丽
张二孩本人空鼻症患者手机号18749871246曾经自杀8刀在河南省人民医院
2023-03-19 回复

空空 ▸ **查理**
怎么缓解?
2023-12-30 回复

查理 作者
不理解，现在缓解的方法很多，缓解的方式很多，为什么还会有人想自杀呢
2023-08-03 回复

不愿聪明的蛋
你好 现在比较有希望的治疗方法是什么呢？ 填充这种越描越黑的就不能算了
2019-12-20 回复

知乎用户I1z8IC ▸ **查理**
1
2023-06-25 回复

查理 作者
zhuanlan.zhihu.com/p/10
按照这个思路去做就好

2020-01-14 回复

寻常

难道没有人关注吗

2019-10-12 回复

江夏锦瑟

加油，看到好难受

2019-05-17 回复

默默默默

鼻甲手术后80%以上的人会出现不适，约20%以上的会发展为空鼻症。我国约3亿鼻炎患者，据理论推算，我国空鼻症患者人数约为600万左右 问题来了 难道3亿人鼻炎都会选择手术?

2019-04-27 回复

ljrmx ▸ **文泓**

20%会变成空鼻症这个概率有点夸张了。假如真的有20%会变成空鼻症，那自然会有很多医生通过论文的方式向社会反馈这个手术的不足，哪怕你说中国的医生在这个大环境下不愿发声，那肯定也会有很多的国外专家去讨论这个问题。但问题是，在所谓的20%概率的支撑下，‘‘空鼻症’’这个疾病都没有得到医学界的认可。再者，要是20%的概率会得空鼻症，那首先医院就不会引进这个技术，毕竟哪个医院不怕医闹呢？一台低温等离子消融的设备，就要几十万起步，大医院每天保守估计要做20台消融手术，一个星期140台手术，造成28个空鼻症患者，那医院的耳鼻喉科估计连窗帘都被撕烂了，还会是现在风平浪静这种表象吗？其实，这个问题的正解，应该是在莆田医院进行鼻甲手术的患者里，有19.99%空鼻症的风险，而正规三甲医院，0.001%。要是真的如这些谣言所说的只要做手术就有20%风险，那全国就没有人敢当耳鼻喉医生了，因为只要学耳鼻喉，就必定要学针对鼻科的手术，不可能一个耳鼻喉医生，一辈子不帮病人做鼻甲手术。所以啊，谣言可谓，这些谣言耽误了多少本可以通过手术解决鼻通气问题的患者，在多少要面临手术的患者心里，插上了一把担惊受怕的刀。

2021-02-18 回复

文泓

十分之一做手术，三千万的20%不就是600万吗?

2019-10-25 回复

一面多能

关注后续

2019-02-01 回复

公车剑

加油

2018-08-13 回复

zzk109

怎么感觉什么病都可与空鼻症有关系，肺还能造血真的还是头一回听说，还是赶快看看文献去，不然又要落伍了。

2018-06-05 回复

火之灵ly

加油!

2018-05-29 回复

李兆强

著作权归作者所有是不是照搬的

2018-05-24 回复

呼吸健康成长

国家不能抛弃这些无辜的人和家庭

2022-06-13 回复

全民小康

请国家关注这些不幸的人，我们空鼻症患者太痛苦了

2022-06-03 回复

小女人

我也是空洞症，就是受蒲田便子的当做的手术，现在才知道后悔晚了，真的是后医症太多了

2022-03-25 回复

Chinese (Simplified) → English

The treatment direction of empty nose syndrome and the ideas for forming the outlet——Charlie

Charlie
Non-volunteers, non-scientific researchers, non-doctors, non-contributors, please leave....

Treatment ideas for the difficult and complicated disease Empty Nose Syndrome——Charlie 2019/2/27 Wednesday

Comprehensive information summary report on work content

These issues can be demonstrated through data and article citations, but the workload is too large, so let' s just boil it down to Charlie' s subjective views. If you have any opinions, please feel free to summarize and comment.

The main problem is:

From the perspective of doctors:
1. The medical community does not know enough about this problem and only focuses on the spiritual aspect to understand it;

2. Most doctors are avoiding this problem, there are too few research doctors, and there is not enough investment in research and development;

3. For their own benefit, a small number of doctors have committed some behaviors that violate academic ethics in the absence of sufficient evidence and data, thereby disturbing the public, reducing social problems and their influence, and thereby shielding or covering up the Putian Department. "Peer".

4. The patient group lacks sufficient information and evidence and does not speak out enough;

A large number of patients have overwhelming negative energy and engage in the following behaviors:

5. Attack and oppose patients who are actively looking for a way out, are in an extremely negative state towards the problem, believe that the disease is incurable, and advise new patients to give up their struggle;

6. Spread negative information and induce other rhinitis patients to undergo surgery at will;

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AIDS);

8. Reluctant to actively share existing information and resources, but instead hide;

9. Eager to get something for nothing, hoping to receive unconditional help but unwilling to give back;

10. Trying every possible means to drag people into trouble but unwilling to use their brains to solve the problem.

Social aspects:

11. The information received is too single and inconsistent, making it easy to be misled;

12. The information coverage is too narrow. We cannot get first-person comprehensive information. We can only briefly understand the problem situation from a third party, and the information will be distorted during the continuous dissemination;

13. The information sent by a small number of patients with empty nose syndrome is confusing and lacks sufficient basis, resulting in society not receiving enough correct information and content;

14. Most of the social content information is too single and focuses on expressing the patient' s pain level. It lacks the description of the principle and the thinking of the solution. It always makes big news but lacks in-depth exploration and medical in-depth, thus further deepening the problem of empty nose. Syndrome issues become horrific social problems and terminal illnesses;

Doctor-patient relationship:

15. There are a lot of doctors who support patients with empty nose syndrome, but not most of them can get appropriate rewards; for example, Wang Xianzhong (with mixed reviews) and Jia Dejing (two patients with empty nose syndrome who are not satisfied with the filling effect) Satisfied and took him to court), not just them, I think, doctors such as Li Guangqi, Zhou Bing, Su Kaiming, etc. have suffered a lot of similar troubles, and even the impact was not small, and they were forced to suspend operations due to pressure. Patients have too low a fault tolerance rate for doctors and their requirements are too harsh. Doctors do not respect the words and ideas of patients and only solve problems based on their own subjective judgment. All problems must be taken together and not treated in isolation.

16. There is a high degree of distrust between doctors and patients, and both parties are concerned about safety issues. As a result, the doctor in question cannot seriously

知乎

Switch mode

17. Due to various personal or other reasons mentioned above, most doctors are indifferent and unclear in their words, or they are directly classified as mental problems; (But in any case, as a top medical student, you respect science and data. Doctors, professors and scholars say that you should never make such a simple judgment that harms other people's families without complete data and arguments, especially since it has become one of the consensus in otolaryngology. I searched and found it but can't find it. Sufficient and reasonable argumentation data and papers.)

18. The safety of doctors cannot be guaranteed, the hospital system is imperfect, and the social system is imperfect. The police at the grassroots level often solve problems in the form of peace and mud, or a big-50 board, which greatly damages the initiative of doctors.

Make a comprehensive summary of the above issues (definitely incomplete and will be completed if you have time)

I proposed the following solutions and solutions (solve the problems in order):

1. Make a summary of all existing information and collect all information related to empty nose syndrome, as well as surgical treatment information, media information, papers, information close to empty nose syndrome, etc.;
2. Summarize and publish the data, and actively share the content of the data, the conclusions of the information summary, and personal opinions;
3. Encourage patients to submit articles to write about their experiences and feelings, and provide editing services to improve the content and information completion;
4. Establish a harmonious mutual aid group that is willing to work together to help each other improve and change, formulate a series of rules, actively share information, visualize the problem, and actively think of multiple solutions according to different problems. Among them, the use of coconut oil is what I am doing. explored among them. Although the participants and participation were not high, this method cultivated collective consciousness, screened collaborators, increased and summarized everyone's experience, and played a very positive role in future direction research and progress (you can understood as a disease treatment incubator);
5. Encourage patients to actively try, record feelings and positive feedback, communicate with everyone about the problem, and identify their own problems and solutions in the long run, thereby strengthening the recognition of the problem and the direction of the solution (stick to the method and content I said) And basically everything that was done actively resulted in at least 80% improvement, and most patients returned to normal life)
6. Actively share medical experience and doctors' opinions in a small area, summarize and exchange medical status and ideological content with each other, and explore its feasibility;

知乎 Switch mode

empty nose syndrome community are excluded from the core mutual aid group and only provide basic information services (to help them Alleviating the disease), thereby ensuring the excellence and efficiency of core members, exploring treatment plans based on the high-quality information provided by each other on the public account and within the group, and releasing them after they have been verified to be effective and universal. However, when some core members have reasonable demands, we will choose to announce the treatment direction and the content that can be released;

8. Actively share and summarize information, and encourage patients to make their voices heard, not just by simply happening, but by comprehensively summarizing their situation;
9. Actively encourage patients to share their experiences and treatment ideas;
10. Through the above content and work, we will actively improve the awareness and understanding of society and the medical community, thereby deepening the understanding and solution of this disease.

The summary of the plan is: form multiple positive closed loops, control access channels, and promote the active development and progress of the content in the closed loops.

Closed loop of patient group improvement:
1. Patients must summarize their problems in all aspects, provide specific feedback, and concretize the problems - 2. Exchange information with each other, expand patient information, and help each other summarize and improve - 3. Expand communication with patients groups, bringing fresh content and knowledge

1-2-3-1 (Establishing a 1-2-3-1 continuous cycle) The problem of nasal valve stenosis was raised by a master after joining in the third step and the information was continuously improved.

Closed-loop improvement of doctor-patient communication:

1. Establish a database of patients' basic knowledge, actively encourage patients to promote and solve problems, weaken patients' dependence on doctors, and improve patients' academic and communication skills————2. Through articles and patient feedback content, from an academic perspective Convince the medical community to correctly understand empty nose syndrome, and combat the medical community that one-sidedly believes that patients with empty nose syndrome are mental illnesses (too little has been done. Academic and sufficient information and data must first be accumulated to facilitate such corrections. At present, This type of data has not been fully summarized, and improved patients are needed to continuously improve this) - 3. Improve the communication bridge between doctors and patients, encourage patients to forgive doctors, and reduce patients' hatred of ordinary doctors and opposition to empty nose syndrome Patients' dependence on doctors encourages patients to discover

知乎

Switch mode

surgical failure rates and improves doctors' understanding of problems. Blind spots——5. Improve the doctor-patient relationship, reduce the surgical failure rate, enhance doctors' alertness and awareness, and improve the understanding of the doctor community

1-2-3-4-5-2 The first step here was established by Charlie, and then gradually realized the continuous cycle from 2-3-4-5-2

Data information is continuously improved in a closed loop:

1. The first step to improve the closed-loop communication between doctors and patients is to establish a database and collect information and articles from internal and external networks - 2. Establish a WeChat public account and actively publish on medical platforms such as Zhihu and other platforms with high academic qualifications and rational communication Articles and videos are uploaded to various media websites. Thereby improving the public's access to information and the completeness of information; continuously strengthening social understanding to further influence doctors' opinions——1. Further improving the data

1-2-1 The core direction of change is doctors' understanding of empty nose syndrome, because only relying on doctors' professional skills and abilities, as well as their research plans, can they cooperate with us to complete the treatment of the disease; (so I suggest that you Patients should be kind to the doctors who support and help us, don't let them get chilled again and again.)

There are three simple closed loops: a closed loop to improve the quality of the patient population, a closed loop to improve doctor-patient communication, and a closed loop to improve data and information. These three loops are interconnected, improving and developing each other. I have been doing it since the beginning, and now it has become a self-contained system that continues to develop; I believe that one day empty nose syndrome will eventually be renamed, all patients will eventually get over it, and doctors will no longer have to worry about it all day long.

Adding a government-level closed loop to these three closed loops means that any complex social problem is not a single problem, but a comprehensive problem. Regarding the phenomenon of empty nose syndrome becoming a difficult and complicated disease, there are problems with the National Health and Family Planning Commission, Baidu, local governments, Putian Medical System, medical system, doctor security system, and qualitative liability system for medical accidents. These problems are big and difficult to change simply.

知乎 Switch mode

bottom up; the other way is that I hope that a group of scientists will qualitatively determine responsibilities and quantitatively analyze each problem, and use a scientific perspective to control and solve it from all angles. question.

Summarize:

Through the above methods, a positive closed-loop group has been formed: summary-sharing-summarization-re-sharing, crowding out negative energy and negative information, constantly accumulating positive energy, and influencing qualitative change from good quantitative change (the core and goal of qualitative change is Change overall doctors' research and views on empty nose syndrome); and constantly select the right people to help, expand reasonable social influence, improve social cognition and doctor cognition, thereby changing the social impression of empty nose syndrome; improve patients Comprehensive quality, improve and increase core group content and understanding.

When the information perfection reaches a certain level, the core group and the core closed loop will gradually weaken, but will not disappear; in the future, more capable people will rise and join, and these contents will gradually spread to most patient groups. in; these patients again form more small or large groups and actively feedback the content (in progress), thus further increasing the positive impact.

tail:

This is my comprehensive treatment idea for outlet construction and management: pigs can fly when standing on the outlet. Establishing appropriate needs through improving cognition is my disease treatment and operation idea; the most important of which is everyone and the doctor. Keep working hard, if I say I have done something, it is probably to build and promote the formation of this outlet.

This is the idea I had at the beginning, and now I will share it with you after gradually improving it. This article will be named the treatment direction of empty nose syndrome and the idea of forming the outlet. I also hope it can also bring benefits to other groups of patients with difficult and complicated diseases. ideas and direction.

This article may be a little arrogant and may make people uncomfortable; but you, readers, it doesn't matter whether you admit my opinions or not. Whether you are happy, disappointed, melancholy or other emotions, they are all the same. I don't have much to do with it; these are just my ideas and methods for disease treatment and changes in the general environment, and I have been slowly working in this direction.

知乎

Switch mode

This article was written in one piece, but it was written in one breath. There will definitely be some dissatisfaction, but it basically reflects my thoughts. The content is not important, but the idea is the most important. This is also where the public account has been promoted and promoted. Finding the right idea is the key to solving the problem.

Everything is so simple that it can be reduced to this sentence: create an automatic accumulation and evolution process, accumulate the good ones, ignore or attack the bad ones, and use quantitative changes to promote qualitative changes.

Many times, those variables are there, and all you need to do is: push in key places, and the tuyere will be formed; everything is like adding a catalyst to a chemical reaction.

——Charlie

Published on 2020-01-06 21:34

medicine empty nose syndrome healthy

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no comments

Chinese (Simplified) → English

空鼻综合征治疗方向以及风口形成思路———查理

查理
非志愿者，非科研工作者，非医生，无贡献的，请走值乎，光阴寸断

疑难杂症之空鼻综合征治疗思路————查理 2019/2/27 星期三

工作内容综合信息总结报告

这些问题都可以通过数据和文章引用来论证，但是工作量太大，就暂且归结于查理的主观看法吧，如有看法，欢迎总结和评论。

主要问题所在：

医生方面：
1. 医学界对于该问题认识不够，一昧地往精神方面去理解；

2. 大部分医生对于这个问题处于逃避状态，研究医生太少，研发投入不够；

3. 少部分医生为了自身利益，在缺乏充足的证据和数据的情况下做出一些违反学术道德的行为，从而扰乱公众视听，减少社会问题以及其影响力，以此来包庇或者掩盖莆田系的“同行”。

4. 患者群体缺乏足够的资料和证据，自身发声不够；

极大部分患者负能量爆表，做出以下行为：

5. 打击和反对积极寻找出路的患者，对问题处于极度消极状态，认为疾病无法医治并且劝新入坑的患者放弃挣扎；

6. 传播负面信息，诱导其他鼻炎患者随意去手术；

7. 对社会持报复主义，渴望更多的患者受害，从而扩大社会影响来促使政府或者社会统一救治（参考艾滋病）；

8. 不肯积极分享现有的信息和资源，反而躲躲藏藏；

9. 渴望不劳而获，希望受到无条件的帮助却不肯回馈；

10.千方百计拖人下水却不愿意动点脑子去解决问题。

社会方面：

11. 接收到的信息过于单一、局面，从而容易被误导；

▲ 赞同 12 ▼ 17 条评论 分享 喜欢 收藏 申请转载 ···

12. 信息面太窄，得不到第一人称的全面信息，只能从第三方简单了解问题情况，而信息在不断传播中也会失真；

13. 少部分空鼻综合征患者发出的信息混乱以及缺乏足够的根据，导致社会得不到足够正确的信息和内容；

14. 大部分社会内容信息过于单一和着重于表达患者痛苦程度，缺乏对于原理的叙述以及解决方案的思考，总是搞个大新闻却缺乏深入的探索与医理上的深入，从而进一步加深空鼻综合征问题变成恐怖的社会难题、绝症；

医患关系方面：

15. 在支持空鼻综合征患者的医生数量并不少，但是不是绝大部分能够得到合适的回报的；比如说王先忠（褒贬不一），贾德静（两位空鼻综合征患者对于填充效果不满意把他告上了法庭），不仅仅是他们，我认为，李光启，周兵，苏开明等医生都受到过很多类似的困扰，甚至影响不小，受到压力被迫暂停手术。患者对于医生容错率太低，而且要求太苛刻，医生不够尊重患者的话语和想法一昧的按照自己的主观判断来解决问题，任何的问题都要综合起来看不得孤立对待。

16. 医生患者双方的高度不信任，双方都对于安全问题产生担忧，导致问题医生不能认真总结问题，患者也无法积极和全面反馈充足的内容，共同推进方案的解决。

17. 由于种种上文所述的个人或者其他原因，大部分医生态度冷漠和言语不详，或者直接归类于精神问题；（但是无论如何，您，作为一位医护人员高材生，尊重科学和数据的医生教授学者，说什么也不该在数据和论证不齐全的情况下轻率得做出如此祸害他人家庭的简易判断，尤其是还成为了耳鼻喉科的共识之一，我前后搜索却找不到充足合理的论证数据还有论文。）

18. 医生安全性得不到保障，医院制度不完善，社会制度不完善，基层警察经常以和稀泥，或者各大50大板的形式解决问题，导致医生的主动性大大受损。

对于以上问题进行综合总结（肯定不全，待补齐，如果有空得话）

我提出了以下解决方案和解决方向（按照顺序去解决问题）：

1. 对于现有的所有资料做出一份总结，搜集所有和空鼻综合征相关的资料，以及手术治疗信息，媒体信息，论文，与空鼻综合征接近的资料信息等等；
2. 把资料进行总结和发布，积极分享资料内容和信息总结的结论以及个人看法；
3. 鼓励患者进行投稿写出自己的经历和感受，并且为此提供编辑服务，完善内容和信息完成度；
4. 建立一个和谐的肯一起进行互相帮助提升改变的互助小组，制定一系列规矩，积极得分享资料信息，把问题具象化，根据不同的问题积极思考多种解决方案，其中椰子油的使用就是我在其中探索出来的。虽然参与者和参与度都不高，但是通过这种方式培养了集体意识，进行了合作人员的筛选，增加并且总结了大家的经验，对未来的方向研究和进展起到了非常积极的作用（可以理解为疾病治疗孵化器）；
5. 鼓励患者积极尝试，记录感受和积极反馈，和大家交流问题的看法，长期下去来确认自己的问题和解决方法，从而加强问题的确认度和问题的解决方向（按照我说的方法和内容坚持下去并且积极去做的基本上都得到至少80%以上的改善，大部分患者恢复正常生活）
6. 小范围内积极分享就医体验和医生的观点，相互总结和交流医学现状和思想内容，对其可行性进行探索·

7. 大力维护肯做出贡献的患者，并且对这部分患者进行信息帮助，不肯为空鼻综合征社群进行维护和提升的群体，排斥他们进入核心互助群体，只是提供基本信息服务（以助其缓解病情），从而保证核心成员优良度和高效，在公众号以及小组内部互相提供的优质信息的条件下探索治疗方案，在经过验证有效和具有普适性之后，发布出来。但是，涉及到一些核心成员出于合理的诉求的情况下，我们会选择公布治疗方向和能发布的内容；
8. 积极分享和总结信息，鼓励患者发出自己的声音，不是简单得发生，而是全方面总结自己的情况；
9. 积极鼓励患者去分享自己的经历经验，和治疗思路方向；
10. 通过以上内容和工作，积极改善社会以及医生团体的认知和理解度，从而加深对于这种疾病的理解和解决方向

方案总结是：形成多个积极闭环，控制进入渠道，促使闭环里面的内容积极发展进步。

病患群体提升闭环：
1.患者全方面得总结自己的问题，反馈具体内容，具象化问题————2.互相交流信息内容，扩大患者信息面，互助总结提升————3.扩大交流患者群体，带来新鲜内容和知识

1-2-3-1（建立1-2-3-1不断循环）鼻阀鼻瓣区狭窄问题就是在第三步中由一位大神加入后提出并且不断进行信息完善的

医患交流改善闭环：

1.建立患者基本知识数据库，积极鼓励患者推动和解决问题，弱化患者对于医生群体的依赖性，提升患者的学术性和交流沟通度————2.通过文章以及患者反馈内容，从学术性说服医生群体正确认识空鼻综合征，打击片面认为空鼻综合征患者是精神类疾病的医生群体（做得太少，必须先积累学术性和足够的资料和数据才方便进行如此改正，而目前这类数据都没有充分得被总结出来，需要提升的患者来不断完善这点）————3. 完善医患关系沟通桥梁，鼓励患者原谅医生，并且降低患者对于普通医生和反对空鼻综合征患者的医生的依赖度，鼓励患者自己发现问题，通过研究和发现来改变社会现象，从而进一步降低医生的手术和治疗风险————4. 从而减少了患者的手术失败率，提升医生对于问题的盲点————5.改善医患关系，降低手术失败率，提升医生警觉和意识，改善医生群体的认识

1-2-3-4-5-2 这里第一步是我查理建立的，然后逐步实现从2-3-4-5-2的不断循环

资料信息不断完善闭环：

1.医患交流改善闭环第一步，数据库建立，收集内外网资料信息和文章————2. 建立微信公众号，在医疗平台，知乎等高学历和理性交流度较高的平台积极发布文章，将视频传到各种媒体网站上面。从而改善公众信息接触面，以及信息完善度；不断加强社会认识方面改善，从而进一步影响医生的看法————1. 进一步完善数据

1-2-1 核心改变方向就是医生对于空鼻综合征的认识，因为只有靠着医生专业的技术和能力，还有他们的研究的方案，才能配合我们完成疾病的治疗；（所以我建议各位患者们善待支持和帮助我们的医生，

简单的三个大致闭环： 患者群体素质提升闭环，医患交流改善闭环，资料信息完善闭环，这三个环相互连接，相互完善促进和发展。从一开始我带着做，到现在自成体系不断发展；我相信空鼻综合征终有被正名的一天，所有的患者们终有熬出头之日，医生们也不用整天担惊受怕的了。

在这个三个闭环上面再增加一个政府层面的闭环，任何复杂的社会问题都不是单一的问题，而是综合性的问题。在空鼻综合征问题成为疑难杂症的现象上面，卫计委，百度，地方政府，莆田系医疗，医疗系统，医生保障系统，医疗事故定性追责系统都是存在问题的。这些问题都是一些大的，难以简单改变的问题。

一种是三种闭环积极发展，自下而上积极推动变革；另外一种方式，我渴望由一批科学家来定性定责定量分析每个问题，以科学的角度来从各个角度把控和解决问题。

总结：

通过以上方式，目前已经形成了一个：总结-分享-总结-再分享 的积极闭环团体，把负能量和消极信息排挤出去，不断积累积极能量，从好的量变影响质变（质变的核心和目标是改变整体医生对于空鼻综合征的研究和看法）；并且不断筛选合适的人进行帮助，扩大合理的社会影响力，改善社会认知和医生认知，从而改变空鼻综合征社会印象；提升病友综合素质，改善并且增加核心团体内容和认识。

当信息完善度到一定程度时，核心团体和核心闭环都会感慢慢弱化，但不会消失；未来会有更多有能力的人会兴起和加入，并且逐步将这些内容扩散到大部分病友群体中；这些病友们再次组成更多的或小或大的团体，并且积极反馈内容（正在进行中），从而进一步增加积极的影响。

尾：

这就是我的综合治疗思路风口建设和管理思路：站在风口上猪都能飞起来，通过改善认知来建立合适的需求就是我的疾病治疗和运营思路；其中最重要的还是大家和医生的不断努力，如果说我做了些什么，那大概就是搭建了和推动了这个风口的形成吧。

这个就是我一开始就有的思路，现在逐渐完善后分享给大家，这篇文章就命名为空鼻综合征治疗方向以及风口形成思路吧，也希望也能对其他的疑难杂症患者群体带来思路和方向。

这篇文章，可能写得有些自大，或许有些让人不舒服；但是您，读者们，您承认不承认我的看法和观点内容都无所谓，无论您高兴开心失落惆怅还是其他的情绪，都和我没有太大的关系；这只是我的对于疾病治疗的思路和方法，以及大环境改变的思路，我也是一直照着这个方向慢慢去做的。学会用大家的力量而不是依靠自己的能力和精力，这是我对于这个疾病的思路和做事方法。

此文囫囵写完，但是是一口气写完的，定会有不如意的地方，但是也基本上反映了我的思路。内容不重要，而思路最为重要，这也是公众号一直宣传和推广的地方，找准思路是解决问题的关键。

所有内容
变促质变

很多的时候，那些变量就在那里，你需要做的就是：在关键的地方推一下，风口就形成了；一切就像化学反应中加入了催化剂一样。

——查理

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医学 空鼻综合征 健康

暂无评论

Lele Tao ···

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空鼻症患者及社会各界爱心人士致国家卫生健康委员会的一封联名信
尊敬的国家卫生健康委员会：
您好！我们是空鼻症患者群体，由患者和患者家属、朋友自发组成，我们的宗旨是为患者提供帮扶救助，心理疏导和情感关怀，让大家能够互助关爱、充满正能量、树立战胜疾病的信心、和谐医患关系。同时为大众科普空鼻症知识和预防措施。我们四处奔走呼吁，希望国家早日承认空鼻症这个疾病，争取让患友有病可医，让在疾病煎熬和焦急中苦苦等待的空鼻症患者能感觉到社会的温暖和生活的曙光，得到社会广泛认可和支持, 不再有被社会抛弃的感觉，促进社会和谐进步。
空鼻症最早由美国医生提出，近几年才逐渐被国人所知晓，但还没引起医疗界重视和认可。
空鼻症： 既空鼻症候群或空鼻综合征，简称空鼻症，英语：Empty Nose Syndrome，缩写：ENS。空鼻症是一种医源性慢性衰竭性疾病。这个病主要是后天获得性疾病，主要由外部原因导致，主要由鼻甲手术、腐蚀、外伤等破坏黏膜导致，如：鼻甲切除、等离子消融、药物腐蚀等手术,及车祸、烧伤、化学品腐蚀、美容等外力伤害导致的呼吸功能障碍及一系列全身严重并发症。是一种后果严重、不可逆的、持续恶化、无法医治的疾病，是世界性难题。病情严重的患者时有猝死和不堪折磨而自杀的惨剧发生。
自上世纪九十年代以来，鼻炎手术大量普及，且在2010年前后达到高峰，但却造成了大量的空鼻症患者（即鼻甲黏膜损伤后遗症）。因为不堪忍受非人的折磨，加上失去劳动能力，全世界都没有治疗方法，让空鼻症患者彻底失去了生活的信心和希望，患者猝死和自杀事件时有发生，2016年北京画家诗人狄月媚、大连小伙刘文涛、新疆女孩张瑞、一个江西空小伙先后跳楼自杀，2017年10月06号，23岁的山东科技大学学生陈志聃在钱塘江投江自杀。2013年前后，山西运城18岁高中女孩和襄阳市30岁的年轻妈妈李燕在鼻炎手术后在睡觉时猝死……,这些事件的发生强烈的震撼着每一位空鼻症患者，我们必须要向社会各界发出我们的求救声，让社会各界、各级政府能够看到空鼻症患者的生存症状，给在疾病煎熬中苦苦等待的每个空鼻症患者家庭一份希望、一个出路。我们想要好好活下来！我们需要研究治疗方法！
在此，我们含泪请求国家卫生健康委员会救救这个灾难深重的群体：
为了减轻社会负担，同时也为了约数百万空鼻症能重燃生活的希望和信心，为了社会和谐安宁，为了我们能重回社会、重回工作岗位、为了无数家庭的健康幸福，我们呼吁社会各界引起重视，正视空鼻症这个问题，中国有3亿鼻炎患者，谁又能保证他们不会成为下一个空鼻症呢？ 在此含泪再次请求国家能倾听我们的心声，伸出援手，能重视我们的诉求，让空鼻症患者有个出路和希望：
1、 请求国家卫生健康委员会能把 “空鼻症”纳入疾病目录，让约600万患者得到确诊。
2、 请求国家卫生健康委员会根据致残程度轻重对空鼻症给出伤残等级和鉴定标准，让鉴定机构和司法机构有个明确依据，让患者能得到合理赔偿和低保救助；
3、 请求国家卫生健康委员会能重视这个群体，能把此病纳入政府研究治疗的范围，让广大患者能得到及时有效的治疗，生活有个希望；
4、 请求国家卫生健康委员会能在我们申请公益组织过程中作为主管单位给与批复和支持，造福广大空鼻症患者；
5、 请求加强医疗广告审查力度，杜绝虚假医疗广告，避免更多人受害。
我们急切期待国家的回复！恳求在政府治疗的所有疾病群体中能把空鼻症也包括进来，不要让我们再在门外等待！

空鼻症有哪些病症？
根据国内外耳鼻喉科专家描述及患者自身症状描述收集：
大部分空鼻症患者多有鼻干、鼻疼、通气大、通气凉、鼻腔干燥结痂、黏膜发白发干、鼻甲萎缩、鼻腔宽大、咳嗽、鼻涕倒流、流鼻涕、粘稠鼻腔分泌物、咽干涩疼、眼干涩疼视物模糊、脱发、牙疼、耳阻塞感、头疼、头晕无力、疲劳、困倦乏力、记忆力下降、精力不足、劳动能力下降、注意力无法集中、抑郁挫折或不安或易怒、睡眠困难等全身病症状。
严重的患者甚至产生呼吸困难、窒息、缺氧、胸闷、心慌、气短、头晕无力、腰酸背痛、浑身疼痛、肺纹理增粗、肺功能严重下降、肺部结节、慢性阻塞性肺病、心率失常、骨质疏松、血小板下降、血尿、肠胃

不适、肝部疼痛、内分泌失调、高血压、高血糖、高血脂、全身多器官功能严重下降、全身器官慢性衰竭等严重并发症，患者如同在炼狱里煎熬、生不如死并丧失劳动力，生活质量很差、时刻有生命危险，有些患者甚至发生猝死，更有一些患者受不了这种非人的折磨而绝望自杀。

空鼻症发病机制是什么?

（1）. 鼻甲有感知、加温、加湿、调节、防御、清洁、免疫、共鸣、神经反射等功能。鼻甲被切除后，其包含的海绵体、血管、粘膜及神经被相应切除或消融，鼻甲及粘膜不能再充盈血液导致血供不足、黏膜面积减少、鼻腔粘膜感受器成比例下降、鼻阻力下降、鼻腔调节功能下降、腺体分泌功能破坏等因素共同参与致病。（摘录自医学资料，结合患者病情）

（1）. 鼻甲被认为是神经生长因子的一个来源，鼻腔黏膜有丰富的腺体及感受器，鼻甲黏膜遭到破坏后腺体及感受器的数量下降，加上血供不足、神经生长因子减少，神经再生和愈合困难，鼻甲及黏膜便会逐步萎缩，对气流感觉和传输功能下降，鼻肺、鼻心等反射功能下降，心肺的血气氧和能力发生障碍、严重者导致严重的高铁血红蛋白症，即MetHb。因为MetHb不能携氧和可逆性地释放氧。原来可与氧结合的铁离子部位都失去了电子，与羟基等牢固地结合。MetHb的主要临床表现为缺氧、呼吸困难、头晕为常见临床表现，严重者可导致死亡。这也说明了为什么很多空鼻症患者有窒息、缺氧、呼吸困难、头晕无力等病症。（摘录自医学资料，结合患者病情）

（2）. 鼻阻力 整个呼吸道阻力50%-80%来源于鼻腔阻力。适宜的鼻腔阻力有助于维持周围支气管开放和肺泡扩张，进而保证气体交换顺利进行、维持胸腔负压以利于体循环和肺循环的静脉回流和充足的静脉回心血量。呼气时正常的鼻腔阻力可帮助维持肺容积，且可能间接影响动脉氧合情况。鼻甲切除术或消融术后，鼻腔阻力的下降，气体、黏膜表面的压强差随之减小，致使鼻肺支气管反射的功能异常，呼吸道及肺功能受到影响，并致肺功能恶化，患者出现胸闷气短、呼吸困难，甚至窒息感。（摘录自医学资料，结合患者病情）

（3）. 最新的科学研究表明，鼻子和肺共同组成人体的呼吸系统，鼻子是呼吸的源头和延伸，源头受损必然影响肺功能。肺部不仅用于呼吸，也是参与血液生成的关键组成部分。肺是血小板生物合成的场所，是造血祖细胞的贮库，肺部负责生产超过一半的血小板。（见-《肺的新功能-造血》，结合患者病情）

空鼻症患者有多少人?

据国内外专家提出：鼻甲手术后80%以上的人会出现不适，约20%以上的会发展为空鼻症。我国约3亿鼻炎患者，据理论推算，我国空鼻症患者人数约为600万左右，这个数量远远超过了欧美国家患者的总和，而且我国患者的患病程度远远比其他国家严重，很多患者猝死或无法忍受折磨而自杀。

空鼻症患者的生存状态：

空鼻症患者的生存状况可以用地狱来形容一点不过，我们中的很多人原本都是健康人，却因为缺失了很小一点的鼻甲从此改写人生，掉进黑暗的地狱。呼-吸这个再平常不过的生理运动对我们来说已经变成了奢望，几乎每个人都有呼吸障碍，我们虽然外表无损，身体各器官却无法正常运行，每个人都有一身的毛病，全身器官亮起红灯。

因为空鼻症，还在上学的孩子不能再正常学习，原本美满的家庭夫妻离异、家庭支离破碎，家庭积蓄化为乌有，蒸蒸日上的事业毁于一旦，上无法赡养父母下无力抚养儿女、卖房卖地都看不好这个恐惧的疾病。

因为空鼻症，我们原本健壮的身躯轰然倒塌、不得不躺在病榻之上苟延残喘，呼吸都成问题，原来生龙活虎现在却手无缚鸡之力，身体瀛弱的不及80多岁的老人，变成了被照顾的对象。

因为空鼻症，我们一人得病拖垮整个家族，原本是家庭的顶梁柱和骄傲、公司的业务骨干，现在却完全丧失劳动能力、干不了任何事、被单位辞退，失去了挣钱能力，成了家庭的负担和拖累，我们无脸再见朋友同事，与世隔绝，郁郁寡欢，整个世界只剩下鼻子。

医疗界、社会各界对空鼻症的认知有限：

因为空鼻症目前尚未进入疾病目录，疾病信息不够透明公开，教材也没及时更新，很多耳鼻喉医生都不知道空鼻症这个疾病，很多权威的专家对空鼻症也知之甚少，甚至医学生、医生、医学院教授、还有耳鼻喉科医生自己都成了鼻炎手术的受害者，做了鼻甲切除，成了空鼻症大军的一员，更不要说没有医学常识的普通老百姓了。因为空鼻症的疾病信息不透明，患者到医院就诊造成的误诊率漏诊率达到90%以上，现在还有大部分的鼻炎手术患者依然蒙在鼓里，即便术后深受并发症折磨却不知道自己就是空鼻症患者。空鼻症患者中有人甚至被误诊达40年，直到他的儿女在网上看到我们做的空鼻症科普才知道严重困扰自己父亲多年的病症原来是空鼻症，可这个患者已是垂暮年龄的老翁，几乎被空鼻症困扰半个世纪，可这么多年来

在多家医院就诊却一直不知道问题出在哪里。还有一个湖北宜昌的空鼻症患者多年来一直被认为是肺出了问题，硬生生吃了多年的呼吸科药物也不见好转，甚至还恶化了，直到看到我们的科普才搞明白。也有少数医生知道空鼻症这个疾病，可迫于各种压力不敢告知患者真相，他们也很困惑，因为以前这个鼻甲等离子消融术曾风靡一时，很多医院的耳鼻喉科不惜花大价钱引进这种设备和技术，但没想到国外先进技术存在这么大缺陷，你让这些医生怎么面对他（她）的患者？怎么解释？这确实是个难题！作为患者我们很理解，毕竟现行的医疗科技对人体的认知还远远不够，医疗技术的应用也是在不断的探索实践中推陈出新，日新月异，一项新技术在运用中出现了瑕疵也很正常，但出现偏差请及时修正，让我们能有病可医、能够治疗缓解。毕竟空鼻症有这么大的群体在那儿，是不容忽视的社会问题。

由于现有的科技手段局限及科室诊疗范围限制，大多数空鼻症患者在医院就诊时很难查出鼻甲损伤的问题，但事实上空鼻症患者的疾病更多的是反映在全身其他器官上，比如：肺功能、血液、尿液、心脏、血压、血糖等问题，但由于是鼻子引起的问题，大多数医生很难把鼻子的问题和身体其他器官的病症联系起来，由此造成了空鼻症患者的诊断只能单纯依靠对鼻甲的检查，而不是同其他器官的病症联系起来综合诊断检查，所以也造成了鉴定难、定残难。很多耳鼻喉科医生由此觉得空鼻症患者是心里出了问题，得了抑郁症，家人由开始的同情逐渐变为愤怒和不理解，他们觉得既然医生都检查说没问题，肯定是自己家里人在作、在无理取闹。有的家庭甚至把空鼻症患者强行送到精神病医院接受治疗。

因为现行的教材课本里对空鼻症的描述和诊断几乎是一片空白，空鼻症患者进入诉讼时无法做鉴定而得不到赔偿，法院的驳回理由是无法做伤残鉴定，鉴定机构退鉴的理由是没有对应的伤残鉴定标准。因为无法定残，很多失去劳动的空鼻症患者拿不到残疾证，办不了低保和救助，整个群体陷入孤立无援的境地。当其他疾病群体在为治病的药纳入医保而呼吁时，而我们却连个疾病名称都没有，更不要谈研究治疗了。因为这个疾病没有纳入疾病目录，所以没有任何机构愿意研究，我们成了无药可救的孤儿，我们眼睁睁的看着空鼻症患友们在深渊里挣扎、在生不如死的炼狱里煎熬却束手无策，只能眼睁睁的看着他们走向死亡却无法阻拦。因为看不到治疗和生活的希望，很多患者绝望自杀或走极端来寻求解脱。

因为鼻炎手术来钱快，获利简单，加之患者受害无法鉴定和得到赔偿，很多民营医院很好的利用了这一法律灰色地带，在网络大肆宣传拉客，把老百姓指引到错误的医院接受这种错误的手术，空鼻症患者绝大部分由网络虚假广告和民营医院所误导和伤害，被害者中大部分都是青少年。而这些人本来风华正茂、年富力强，正是干事业的好年龄，却因为空鼻症而毁了一生，由创造社会价值和财富的中坚力量变成了社会的负担，变成了一大社会问题。很多民营医院当时虽然得到了几千元的蝇头小利，却为整个社会带来了无法估量的损失和负担，造成了极其严重的社会问题。

我们注册空鼻症公益组织面临的困境：

为了能让空鼻症能纳入疾病目录，为了研究治疗空鼻症，为了帮扶救助这个灾难的群体，为了研究治疗空鼻症，孙素林和陶杰甚至不惜廉价卖掉上海唯一的房子。四年来他们俩一直在奔走呼吁，为了更好的运行这个组织和提高公信力，空鼻症患者一直在为注册成立为正式的公益组织而努力，从北京到广东到深圳到湖北到上海……，但注册之路却充满了艰辛和挫败感，无数次的被拒之门外，回复是没有业务主管单位卫生健康委员会批准，我们也找了相关地方的卫生健康委员会，回答是不属于他们管，我们真切的感到迷茫和无助，很多时候呆坐在各级民政局大厅或各级卫生健康委员会大门前步履蹒跚，不知道该走向哪里？

作为泱泱大国的患者，我们时常感到汗颜，现在欧美国家早就注册成立了空鼻症患者公益组织，我们却连个疾病名称都没有。每次面对国外患者及公益组织的质疑和追问，我们只有苦笑或避而不谈。因为没有一个正式的公益组织，我们每次出门和其他机构及个人交流，总是被怀疑，我们到底代表谁？我们又能代表谁？我们自己是谁？因为没有组织，我们很难募集到善款；因为没有组织，我们做事说话没有公信力；因为没有组织，我们的活动很难开展；因为没有组织，我们不被认可和关注；……太多太多的艰难困境，希望作为主管部门的卫生健康委员会能批准我们成立空鼻症患者组织，希望民政部能放开胸怀接纳我们。

此致

空鼻症患者群体

> A joint letter from people with empty nose disease and caring people from all walks of life to the National Health and Health Commission
> Dear National Health Council:
> Hello! We are a group of people with empty nose disease, composed of patients and patients' families and friends, our purpose is to provide assistance to patients, psychological guidance and

emotional care, so that everyone can help each other care, full of positive energy, build confidence to overcome the disease, harmonious doctor-patient relationship. At the same time, knowledge and prevention of air nose disease for the general public. We are running around to appeal, hoping that the country will recognize the disease of empty nose as soon as possible, strive to make the patients sick and treatable, so that the empty nose patients who are suffering from illness and anxiety can feel the warmth of society and the dawn of life. It will be widely recognized and supported by the society. It will no longer feel abandoned by society, and promote social harmony

Empty nose disease was first proposed by American doctors, and it has gradually been known by Chinese people in recent years, but it has not attracted the attention and recognition

Empty Nose syndrome: Empty Nose syndrome or empty nose syndrome, abbreviation: ENS. Empty nose is an iatrogenic chronic failure disease. This disease is mainly acquired disease, mainly caused by external causes, mainly caused by nasal nail surgery, corrosion, trauma and other damage to the mucosa, such as: nasal nail removal, plasma ablation, drug corrosion, etc., and respiratory dysfunction caused by external forces such as car accidents, burns, chemical corrosion, beauty and other serious complications. It is a serious, irreversible, continuous worsening, incurable disease, is a worldwide problem. Serious patients have sudden death and suffering and suicide.

Since the 1990s, rhinitis surgery has been widely popular and peaked around 2010, but it has caused a large number of people with empty nasal disease (i.e. the sequelae of nasal nail muc Because of unbearable inhuman torture, coupled with loss of ability to work, there is no cure in the world, so that empty nose patients completely lose confidence and hope in life. Sudden death and suicide incidents occur from time to time. 2016 Beijing painter and poet Di Yuemei, Dalian boy Liu Wentao, Xinjiang girl Zhang Rui, a Jiangxi air boy, successively jumped to suicide. On October 06, 2017, 23-year-old Shandong University of Science and Technology student Chen Zhiqi committed suicide Around 2013, an 18-year-old high school girl from Yucheng, Shanxi, and a 30-year-old young mother from Fuyang, Li Yan, died suddenly in sleep after rhinitis surgery The occurrence of these events strongly shocked every empty nose patient, we must send out our cry for help to all sectors of society, so that all sectors of society and governments at all levels can see the survival symptoms of empty nose patients, and give every empty nose patient family who are waiting in the suffering of the disease a hope and a way out. We want to survive! We need to study cures!

Here, we tearfully ask the National Health and Health Board to save this devastated group:

In order to reduce the burden on society, but also to restore hope and confidence in life for millions of empty nose diseases, for social harmony and peace, for us to return to society, return to work, and for the health and happiness of countless families, we call on all sectors of society to pay attention to the problem of empty nose disease. There are 300 million people suffering from rhinitis in China, who can guarantee Here again, in tears, I ask the country to listen to our voices, reach out to help, and pay attention to our demands, so that empty nose patients have a way out and hope:

Request the National Health and Health Commission to include "empty nose disease" in the list of diseases, so that about 6 million patients can be diagnosed.

2. Request the National Health and Health Commission to give disability levels and criteria for identification of empty nose disease according to the degree of disability, so that the evaluation agencies and judicial bodies have a clear basis, so that patients can get reasonable compensation and low

3. Request the National Health Commission to pay attention to this group, to include this disease in the scope of government research and treatment, so that the majority of patients can get timely and effective treatment, and have

4. Request the National Health and Health Commission to be the competent unit in our application for public welfare organizations to give approval and support to benefit the vast majority of empty nose patients;

5. Request to strengthen the review of medical advertisements, eliminate false medical advertisements, and prevent more victims.
We are eagerly waiting for a response from the country! Pray that empty nose is included in all the disease groups treated by the government, don't make us wait outside the door anymore!

What are the symptoms of empty nose disease?
Collected according to the description of ear, nose and throat experts at home and abroad and the patient's
Most people with empty nasal disease have dry nose, nose pain, large ventilation, cool ventilation, dry nasal cavity, dry mucous membrane, dry hair, dry nose, atrophy, broad nasal cavity, cough, reflux, runny nose, sticky nasal secretions, dry throat, dry eyes, blurred vision, hair loss, toothache, ear blockage, headache, weakness, fatigue, sleepiness, loss of memory, lack of energy, reduced ability to work, inability to concentrate, depression or restlessness or irritability, difficulties sleeping.
Severe patients even have serious complications such as breathing difficulties, asphyxia, hypoxia, chest tightness, panic, shortness of breath, dizziness, back pain, pain in the body, thickening of the lungs, serious decline in lung function, lung nodules, chronic obstructive pulmonosis, heart rate disorders, osteoporosis, platelet drop, hematuria, gastrointestinal discomfort, liver pain, endocrine disorders, high blood blood sugar, high blood lipid, serious decline in multiple organ function throughout the body, chronic failure of the whole body. Patients are like suffering in purgatory, poor quality of life, life is always in danger. Some patients even have sudden death, and some patients can't stand this inhuman death.

What is the pathogenesis of empty nose disease?
(1). Nose armor has functions such as perception, heating, humidification, regulation, defense, cleansing, immunity, resonance, nerve reflex etc. After the nasal nail is removed, the sponges, blood vessels, mucous membrane and nerves contained in it are removed or ablated accordingly. The nasal nail and mucous membrane can no longer fill the blood supply, the mucosa area is reduced, the nasal mucosal receptors are proportionately reduced, the nasal resistance is reduced, the nasal regulatory function is reduced, and the g (Excerpts from medical data combined with patient's condition)
(1). The nasal mucosa is considered to be a source of nerve growth factors. The nasal mucosa has rich glands and receptors. The number of glands and receptors decreases after the damage of the nasal mucosa. The blood supply is inadequate, nerve growth factors are reduced, nerve regeneration and healing difficulties. The nasal and mucous membrane will gradually shrink. The function of airflow perception and transmission is reduced. The reflex function of nasal lungs and nasal heart is reduced. The blood oxygen and ability of the heart and lungs will be dysfunctional. Because MetHb cannot carry oxygen and release oxygen reversibly. The iron ion parts that can be combined with oxygen have lost their electrons and are firmly bonded with hydroxyl groups. MetHb's main clinical manifestations are hypoxia, dyspnea, dizziness are common clinical manifestations, severe cases can lead to death. This also explains why many people with empty nose disease have asphyxia, hypoxia, difficulty breathing, dizziness and weakness. (Excerpts from medical data combined with patient's condition)
(2). Nose resistance 50%-80% of the total respiratory tract resistance comes from nasal resistance. Suitable nasal resistance helps to maintain surrounding bronchial open and alveolar dilate, thus ensuring smooth gas exchange, maintaining negative chest pressure for body circulation and lung circulation, and sufficient blood volume of veins. Normal nasal resistance while exhaling helps maintain lung volume and may indirectly affect arterial oxygenation. After nasal arterectomy or ablation, nasal resistance decreases. The pressure difference between the gas and mucosa surface is reduced, resulting in abnormal function of the nasal lung bronchial reflex, respiratory and lung function is affected, and lung function is deteriorating. The patients experience chest tightness,

shortness of breath, difficulty of breathing, and (Excerpts from medical data combined with patient's condition)
(3). The latest scientific research shows that the nose and lungs together make up the respiratory system of the human body. The nose is the source and extension of breathing. The damage to the source will inevitably The lungs are not only used for breathing, but also a key component involved in blood production. The lungs are the site of platelet biosynthetic, the reservoir of hematopoietic progenitor cells, and the lungs are responsible for producing more than half (See - "New function of the lungs - hematopoietic", combined with patient condition)
How many people have empty nose disease?
According to experts at home and abroad, more than 80% of people will suffer discomfort after nasal nail surgery, and about 20% will develop empty nose. About 300 million rhinitis patients in China, according to theory, the number of empty nose patients in China is about 6 million, this number far exceeds the total of patients in Europe and the United States, and the degree of illness of patients in our country is far more serious than other countries, many patients die suddenly or can not
Survival status of empty nose patients:
The living conditions of empty nose patients can be described as hell but many of us are healthy people, but because we lack a tiny nose armor, we have been rewrite our lives and fall into a dark hell. Breath-in this ordinary physical exercise has become a luxury for us. Almost everyone has respiratory difficulties. Although we are not damaged, the organs of the body can not function normally. Everyone has a problem, the organs of the body are red light.
Because of empty nose disease, the children still in school can no longer study normally. The original happy family husband and wife are divorced, the family is broken, the family savings are gone, the thriving career is destroyed, the parents are unable to support their children, and the homes and land are not able to see the fear of this disease. Because of empty nose disease, our original strong body collapsed. We had to lie on the sick bed and breathe, breathing was a problem. The original live tiger now has no power to tie the chicken. The weak body of the elderly, less than 80 years old, has become the object of care.
Because of empty nose disease, one of us got sick and brought down the whole family. Originally the backbone and pride of the family, the backbone of the company's business, but now we have completely lost the ability to work, can't do anything, was dismissed by the unit, lost the ability to earn money, became a burden and drag on the family. We have no face to see friends and colleagues, isolated from the world
The medical profession and the community have limited awareness of empty nose disease:
Because empty nose disease has not yet entered the disease catalogue, the disease information is not transparent enough, and the teaching materials are not updated in time. Many ENT doctors do not know about empty nose disease, many authoritative experts know little about empty nose disease. Even medical students, doctors, medical professors, and ENT doctors themselves have become victims of rhinitis surgery. They have done nasal acne removal, become a member of the army of empty nose disease, let alone ordinary people without medical knowledge. Due to the opaque information of empty nasal disease, the misdiagnosis rate caused by patients to visit the hospital has reached more than 90%, and now most of the rhinitis surgery patients are still in the dark, even if they suffer from complications after surgery, they do not know that they are empty nose Some people with empty nose disease have even been misdiagnosed for 40 years. It wasn't until his children saw the empty nose disease we did on the Internet that he did not know that the disease that had seriously troubled his father for many years was empty nose disease. But this patient is already an old man of the coveted age. Almost half a century, but for so many years, he has been in many hospitals There is also an empty nose patient in Yichang, Hubei, who has been thought to have a lung problem for many years. The respiratory medicine that he has been taking for years has not improved, or even got worse, until he saw our popular science There are also a few doctors who know the disease of empty

nose disease, can be forced by various pressure to tell the patient the truth. They are also confused, because in the past this nasal armour plasma ablation was popular, many hospitals' otolaryngology department did not hesitate to spend a lot of money to introduce this equipment and technology, but did not expect that foreign advanced technology has such a big flaw, How to explain it? This is really a problem! As a patient, we understand that, after all, the current medical technology is far from enough awareness of the human body, the application of medical technology is also constantly exploring and changing in practice, and it is normal for a new technology to appear flaws in the use of a new technology, but if there are deviations please correct in time, so that we can After all, empty nose disease has such a large group out there, it is a social problem that can't

Due to the limitations of existing scientific and technological means and the limited scope of clinical treatment, it is difficult for most patients with empty nose disease to detect nasal nail damage when they visit the hospital. However, in fact, the diseases of empty nose patients are more reflected in other organs of the body, such as lung function, blood, urine, heart, blood pressure, blood sugar etc. However, due to problems caused by the nose, most doctors have difficulty connecting problems with the diseases of other organs of the body. As a result, the diagnosis of empty nose patients can only rely on the examination of the nose, rather than the comprehensive diagnostic examination of the diseases of other organs, Many otolaryngologist think that the empty nose patients have problems in their heart, have depression, and the family gradually changed from sympathy to anger and incomprehension. They feel that since the doctors have checked that it is no problem, it is definitely their own family members are doing it and making Some families even forced empty nose patients to a mental hospital for treatment.

Because the description and diagnosis of empty nasal disease in the current textbooks is almost blank. When empty nasal disease patients enter the lawsuit, they are unable to make an assessment and receive no compensation. The court dismissed the reason that they could not do a disability assessment, and the reason that the evaluation agency withdrew Because there is no disability, many empty nose patients who have lost their jobs can't get disability certificates, can't get low insurance and relief, and the whole group is in a situation of isolation and assistance While other disease groups are calling for medical coverage for cures, we don't even have a name for the disease, let alone research treatment. Because this disease is not included in the list of diseases, no institution is willing to study it, we become hopeless orphans, we watch empty nose patients struggle in the abyss, suffer in the purgatory of life, but have nothing to do about it. We can only watch them go to death without stopping it. Because there is no hope of treatment and life, many patients desperate to commit suicide or go to extremes to seek relief.

Because rhinitis surgery comes quickly and makes simple profits, and because the victims are unable to identify and receive compensation, many private hospitals have made good use of this legal grey area, hype around the Internet to invite customers and direct people to the wrong hospital to receive this wrong surgery. Most of the empty nose patients are misled and hurt by online false advertisements and private hospitals. Most of the victims are teenagers. These people were born in a prosperous and strong age, and they were the good age for doing business, but they destroyed their lives because of empty nose disease. They turned from the backbone of creating social value and wealth into a burden on society, and became a major social problem. Although many private hospitals received small profits of several thousand dollars at that time, they brought incalculable losses and burdens to the whole society, causing extremely serious social problems.

The difficulties we face with registered empty nose charity organizations:

In order to allow empty nose disease to be included in the list of diseases, in order to study and treat empty nose disease, in order to help rescue the disaster group, and in order to study and cure empty nose disease, Sun Sulin and Tao Jie even sold the For four years they have been running the campaign, in order to better run the organization and improve credibility, empty nose patients have been working hard to register as a formal public welfare organization, from Beijing to Guangdong to

> Shenzhen to Hubei to Shanghai... However, the road to registration is full of hardship and frustration, countless times have been turned away. The reply is that there is no approval from the health and health committee of the business competent unit. We also sought the health and health committee of the relevant local area. The answer is that it does not belong to them. We really feel confused and helpless. Many times sitting in the halls of civil affairs bureaus at all levels or the health and
> As a patient in a big country, we often feel shame. Now European and American countries have long registered the establishment of public welfare organizations for empty nose patients, but we don't even have a disease name. Every time we face questions and questions from foreign patients and public welfare organizations, we only laugh bitterly or avoid talking about it. Because there is no formal public welfare organization, every time we go out and communicate with other institutions and individuals, we are always questioned. Who do we represent? Who else can we represent? Who are we? Because there is no organization, it is difficult for us to raise funds; because there is no organization, we have no credibility in what we do and say; because there is no organization, our activities are difficult to carry out; because there is no There are too many difficult difficulties. I hope that the Health and Health Commission, as the competent department, will approve the establishment of an empty nose patient organization. I hope the Ministry of Civil Affairs will open its
> 此致
> Empty nasal patients

Lele Tao

空鼻症患者及社会各界爱心人士致国家市场监督管理总局的一封联名信
尊敬的国家市场监督管理总局:
您好！我们是空鼻症患者群体，由患者和患者家属、朋友自发组成，我们的宗旨是为患者提供帮扶救助，心理疏导和情感关怀，让大家能够互助关爱、充满正能量、树立战胜疾病的信心、和谐医患关系。同时为大众科普空鼻症知识和预防措施。我们四处奔走呼吁，争取让患友有病可医，得到社会广泛认可和支持，不再有被社会抛弃的感觉，促进社会和谐进步。
空鼻症： 既空鼻症候群或空鼻综合征，简称空鼻症，英语：Empty Nose Syndrome，缩写：ENS。空鼻症最早由美国医生提出，近几年才逐渐被国人所知晓，但还没引起医疗界重视和认可。
空鼻症是一种医源性慢性衰竭性疾病。这个病主要是后天获得性疾病，主要由外部原因导致，主要由鼻甲手术、腐蚀、外伤等损伤了鼻甲及黏膜导致，如：鼻甲切除、等离子消融、药物腐蚀等,及车祸、烧伤、化学品腐蚀、美容等外力伤害导致的呼吸功能障碍及一系列全身严重并发症。是一种后果严重、不可逆的、持续恶化、无法医治的疾病，是世界性难题。病情严重的患者时有猝死和不堪折磨而自杀的惨剧发生。据国内外专家提出：鼻甲手术后80%以上的人会出现不适，约20%以上的会发展为空鼻症。我国约3亿鼻炎患者，据理论推算，我国空鼻症患者人数约为600万左右，
我们了解到近几年已先后有10人不堪折磨自杀，2人猝死。这些事件的发生强烈的震撼着每一位空鼻症患者，我们必须要向社会各界发出我们的求救声，让社会各界、各级政府能够看到空鼻症患者的生存症状，给在疾病煎熬中苦苦等待的每个空鼻症患者家庭一份希望、一个出路。

空鼻症有哪些病症?
根据国内外耳鼻喉科专家描述及患者自身症状描述收集:
大部分空鼻症患者多有鼻干、鼻疼、通气大、通气凉、鼻腔干燥结痂、黏膜发白发干、鼻甲萎缩、鼻腔宽大、咳嗽、鼻涕倒流、流鼻涕、粘稠鼻腔分泌物、咽干涩疼、眼干涩疼视物模糊、脱发、牙疼、耳阻塞感、头疼、头晕无力、疲劳、困倦乏力、记忆力下降、精力不足、劳动能力下降、注意力无法集中、抑郁挫折或不安或易怒、睡眠困难等全身病症状。
严重的患者甚至产生呼吸障碍、血氧合成障碍、呼吸困难、窒息、缺氧、胸闷、心慌、气短、头晕无力、浑身疼痛、肺纹理增粗、肺功能严重下降、肺部结节、哮喘、慢性阻塞性肺病、高铁血红蛋白症、心率失常、骨质疏松、血小板下降、血尿、蛋白尿、肠胃不适、肝部疼痛、内分泌失调、高血压、高血糖、高血脂、全身多器官功能严重下降、全身器官慢性衰竭等严重并发症，患者如同在炼狱里煎熬、生不如死并丧失劳动力，生活质量很差、时刻有生命危险，有些患者甚至发生猝死，更有一些患者受不了这种非人的折磨而绝望自杀。

虚假医疗宣传广告和莆田系滥用鼻炎手术是导致空鼻症的主要元凶:
我国优质的公立医院几乎没有打广告的，也不需要打广告，打广告的几乎都是劣质的莆田系医院，这些医院为了钱无所不用，百度宣传是他们获得客源的主要手段。这些莆田系医院为了加大网络宣传力度，不惜注册多个网站、网址和域名，变着法的宣传，而老百姓获取网络信息的渠道有限、医疗信息不对称和匮乏，百度又是中国老百姓进入网络的主要入口，几乎垄断者老百姓获取网络信息的入口，几乎没有选择权，这也是百度莆田系医疗广告肆无忌惮的主要原因之一。
空鼻症受害者绝大部分是被百度虚假医疗宣传和莆田系医院所害。因为鼻炎手术来钱快，获利简单，加之空鼻症得不到认可、受害者无法鉴定和得到赔偿，违法成本为零更加助长了百度和莆田系的野蛮生长和发展。很多莆田系民营医院很好的利用了法律灰色地带，在网络大肆宣传拉客，把老百姓指引到错误的医院接受这种错误的手术，空鼻症患者绝大部分由百度虚假医疗宣传、广告所误导和指引，被指引到莆田系民营医院被做了错误的鼻甲消融术，很多人根本不是鼻炎患者，没有任何鼻部不适，也被故意说成与鼻子有关，活生生把好好的鼻甲给消融切除了。被害者中大部分都是青少年，而这些人本来风华正茂、年富力强，正是干事业的好年龄，却因为空鼻症而毁了一生，由创造社会价值和财富的中坚力量变成了社会的负担，变成了一大社会问题。

竞价排名广告是百度的主要收入来源，而医疗广告的收入约占百度广告收入的50%，民营医院的客源病源主要依靠百度广告宣传推广，当时一例鼻炎手术虽然为他们获得了几千元的蝇头小利，却为整个社会带来了无法估量的损失和负担，导致了数百万的受害者，造成了极其严重的社会问题。
医疗广告社会危害重大，医疗事关百姓生死，一人被害全家遭殃，几代人积蓄化为乌有不说，整个家族倾家荡产。受害者事业、家庭、财富因此不复存在，后续治疗还是个无底洞，受害者也因此陷入无休止的病痛折磨。
医疗广告不仅危害百姓的生命健康，同时更是危害了政府和整个社会安全和谐，这些受害者被害前是社会价值得创作者，被害后成为家庭和社会的负担和拖累，因为失去劳动能力，医疗、养老、低保救助等都需要政府承担，无形中造成了无法估量的国家损失。同时因为被害，政府公信力受到质疑，社会安宁和谐被破坏，直接激化了医患关系和社会矛盾，造成了劣币驱逐良币现象，政府和公立医院成了百度莆田系作恶的背锅侠，同时还让那些信誉品质良好的其他民营医院受到影响。莆田系医院的民生狼藉影响了整个民营医院的生态圈，对整个医疗体系改革造成了重创和极坏的影响。
空鼻症受害者的心声和诉求：
在此，我们请求：
1、请求国家市场监督管理总局加强网络监管，禁止医疗广告，给老百姓一个安全的就医环境，避免更多人受害；
2、要求严惩百度虚假医疗宣传广告，让百度承担其法律责任和赔偿责任，还受害者一个公道；
3、要求对莆田系网站注册备案力度的审查监管力度，很多莆田系医院同时注册多个网站和域名在网络打广告，强烈要求限制其网站及域名数量，出台明确法律法规；
4、要求严惩莆田系虚假医疗宣传广告，加倍赔偿受害者并承担法律责任，强烈要求出台明确法律法规。
此致
空鼻症患者群体

> A joint letter from patients with empty nose disease and caring people from all walks of life to the State Administration of Market Supervision and Administration
> Dear State General Administration of Market Supervision:
> Hello! We are a group of people with empty nose disease, composed of patients and patients' families and friends, our purpose is to provide assistance to patients, psychological guidance and emotional care, so that everyone can help each other care, full of positive energy, build confidence to overcome the disease, harmonious doctor-patient relationship. At the same time, knowledge and prevention of air nose disease for the general public. We are running around and calling for patients to be cured, to be widely recognized and supported by society, to no longer feel abandoned by society, and to promote social harmony and progress.
> Empty Nose syndrome: Empty Nose syndrome or empty nose syndrome, abbreviation: ENS. Empty nose disease was first proposed by American doctors, and it has gradually been known by Chinese people in recent years, but it has not attracted the attention and recognition
> Empty nose is an iatrogenic chronic failure disease. This disease is mainly acquired disease, mainly caused by external causes, mainly caused by nasal nail surgery, corrosion, trauma, etc. damage to the nose and mucous membrane, such as: nasal nail removal, plasma ablation, drug corrosion, etc., as well as respiratory dysfunction caused by external injuries such as car accidents, burns, chemical corrosion, cosmetic and other serious complications of the body. It is a serious, irreversible, continuous worsening, incurable disease, is a worldwide problem. Serious patients have sudden death and suffering and suicide. According to experts at home and abroad, more than 80% of people will suffer discomfort after nasal nail surgery, and about 20% will develop empty nose. There are about 300 million rhinitis patients in China. According to theory, the number of empty nose patients in China is about 6 million.
> We know that in recent years, 10 people have committed suicide and 2 have died suddenly. The occurrence of these events strongly shocked every empty nose patient. We must send out our cry for help to all sectors of society, so that all sectors of society and governments at all levels can see the

survival symptoms of empty nose patients, and give every empty nose patient family who are waiting in the suffering of the disease a hope and a way out.

What are the symptoms of empty nose disease?
Collected according to the description of ear, nose and throat experts at home and abroad and the patient's
Most people with empty nasal disease have dry nose, nose pain, large ventilation, cool ventilation, dry nasal cavity, dry mucous membrane, dry hair, dry nose, atrophy, broad nasal cavity, cough, reflux, runny nose, sticky nasal secretions, dry throat, dry eyes, blurred vision, hair loss, toothache, ear blockage, headache, weakness, fatigue, sleepiness, loss of memory, lack of energy, reduced ability to work, inability to concentrate, depression or restlessness or irritability, difficulties sleeping.
Severe patients even develop respiratory disorders, blood oxygen synthesis disorders, breathing difficulties, asphyxia, hypoxia, chest tightness, heart panic, shortness of breath, dizziness, weakness, pain, thickening of lung texture, serious decline in lung function, lung nodules, asthma, chronic obstructive pulmonary disease, high iron hemoglobin, heart rate disorders, osteoporosis, platelet decline, hematuria, proteinuria, gastrointestinal discomfort, liver pain, endocrine disorders, high blood blood sugar, high blood lipids, severe decline in multiple organ function, chronic failure of the whole body organs. The patient is like in purgatory, life is worse than death and loss of labor. The quality of life is very poor and life is life in danger

False medical advertising and abuse of rhinitis surgery in the field are the main culprits for empty nose:
China's high-quality public hospitals are almost no advertising, no need to advertise, advertising is almost all poor-quality Putian hospital, these hospitals do nothing for money, Baidu publicity is their main means to get customers. In order to increase network publicity, these Putian hospitals are willing to register multiple websites, web sites and domain names, changing the law of publicity. While the channels for ordinary people to obtain online information are limited, medical information is asymmetrical and lack. Baidu is the main entry point for Chinese people to enter the network, almost monopoly people to obtain online information, almost no choice. This is also one of the main reasons why Baidu'
Most of the victims of empty nose disease were killed by Baidu's false medical publicity and the Putian Hospital. Because rhinitis surgery comes quickly and profits are simple, coupled with the lack of recognition of empty nose disease, the victims cannot be identified and compensated, the illegal cost is zero, and the barbaric growth and development of Baidu's field system is Many private hospitals in Putian have made good use of the legal grey area. They have been hypeinged on the Internet to invite people to the wrong hospital to receive this kind of wrong surgery. Most of the empty nose patients are misled and guided by Baidu's false medical publicity and advertisements. They are directed to the Putian private hospital to have wrong nasal artery ablation. Many people are not rhinitis patients at all, have no nose discomfort. They are also deliberately said to be related to the nose. They are ablation and removal of good Most of the victims are young people, and these people are born in a prosperous and strong age, and they are the good age to do business, but they have ruined their lives because of empty nose disease. They have turned from the backbone of creating social value and wealth into a burden on society, and become a major social
Bidding ranking advertising is Baidu's main source of income, while medical advertising revenue accounts for about 50% of Baidu's advertising revenue, private hospitals' source of disease mainly rely on Baidu advertising promotion, when a case of rhinitis surgery, although they received thousands of dollars of small profit, but brought incalculable losses and burden to the whole society, resulting in millions of victims, causing extremely serious
Medical advertising society is very dangerous. Medical care is a matter of life and death for the people. One person is killed and the whole family suffers. The savings of several generations are

gone. The whole family is The victim's career, family, and wealth are gone, and the follow-up treatment is still a bottomless hole, and the victim is suffering from endless illness.
Medical advertising not only endanger the lives and health of the people, but also endanger the security and harmony of the government and the whole society. These victims are the creators of social value before being killed, and become a burden and drag on the family and society after being killed. Because the loss of the ability to work, medical care, old-age care, and low-income At the same time, the credibility of the government was questioned, and social peace and harmony was destroyed, directly aggravating the relationship between doctors and patients and social conflicts, causing bad money to drive out good money. The government and public hospitals became the backers of Baidu's sodian system. At the same time, other private hospitals with good reputation and The people's livelihood in Putian Hospital has affected the entire private hospital ecosystem, and has caused serious damage and bad impact on the reform of the entire medical system.
Voice and appeal of victims of empty nasal disease:
Here we request:
1, request the State Administration of Market Supervision and Administration to strengthen network supervision, ban medical advertising, give the people a safe environment for medical treatment, and avoid more victims;
2. Requires strict punishment for Baidu's false medical publicity advertisements, let Baidu bear its legal responsibility and liability, and give justice to the victims;
3. Requires the review and supervision of the registration and filing of the Putian website. Many Putian hospital registered multiple websites and domain names at the same time to advertise on the Internet, strongly demanding to limit the number of their websites and domain names, and introduce
4. Requires severe punishment for false medical propaganda advertisements in the field, double compensation for victims and bear legal responsibility, and strongly demands clear laws and regulations.
此致
Empty nasal patients

⚙ · Hide Translation ·

The Wayback Machine - https://web.archive.org/web/20231107173016/https://www.nytimes.com/2018/11/15/...

The New York Times

Scandals Catch Up to Private Chinese Hospitals, After Fortunes Are Made

The Putian network of 8,000 facilities, which expanded rapidly with little government oversight, is facing national outrage and scrutiny over a death and fraud allegations.

By Sui-Lee Wee

Nov. 15, 2018

PUTIAN, China — Chen Deliang, wearing an orange tunic, a gold watch and fluffy bedroom slippers decorated with snowflakes and the word "Love," stood proudly in the 130,000-square-foot temple he had built. He had filled it with pagodas, Buddhas and a towering statue of a local goddess. There were several wings, with bedrooms and an office where he practiced calligraphy.

A chain smoker with a wispy beard, he initially hesitated talking about his path to unimagined wealth, but eventually relented with a matter-of-factness that betrayed no sense of smugness: "I was the first person to create everything."

Nearby his family and friends owned mansions, many several stories tall, rising above the unpaved roads and sweet potato fields of the village of Dongzhuang in southern China. They exuded a gaudy opulence — elevators, minarets, gilded gates, fountains with Greek gods. Just days before the Lunar New Year, the most important festival in China, Ferraris and Lamborghinis lined their driveways.

Even in a country where multimillionaires are minted daily, Mr. Chen and his brethren are unlikely testaments to the Chinese dream. A middle school dropout turned martial arts performer turned itinerant salesman, Mr. Chen parlayed a remedy to treat scabies into a chain of clinics for sexually transmitted diseases and then into the country's largest network of private hospitals. Along the way, his relatives and neighbors in Dongzhuang and the surrounding area of Putian got into the same business and also made lots of money.

"All of us were from Dongzhuang, and one by one, we started engaging in medicine," Mr. Chen said. "It was your relatives, his relatives — all of us were relatives."

Chen Deliang founded the network decades ago after making money selling his own remedy for scabies. Today, eight in 10 private hospitals in China are affiliated with the Putian system.
Sui-Lee Wee

The Putian system, a loosely affiliated network that traces back to Mr. Chen's initial forays into medicine, accounts for eight of every 10 private hospitals in the country, some 8,000 facilities. Although they don't all have the same owners, all were started by people with connections to the area of Putian and are members of the same trade group.

They offered a vision of the future of medicine, promising everything the old state hospitals lacked, like well-trained specialists, quick appointments at the

click of a mouse and state-of-the-art equipment. Public officials praised the hospitals, while big Wall Street firms invested billions of dollars in them.

Then came the scandal. A university student died after a doctor at a Putian-linked hospital tried to treat his cancer with a discredited form of immunotherapy. The case prompted nationwide outrage and protests. Shares of Putian-linked hospitals plummeted. The government announced an investigation into Putian ads.

For the Chinese leadership, the death has exposed weaknesses in the country's health care system. While public hospitals are subject to tighter scrutiny at the national level, private hospitals like those in the Putian network are largely overseen by local governments, many of which don't have the resources and expertise to police the medical profession.

Some hospitals in the Putian group fabricated patients' testimonies and doctors' credentials. Others listed false certifications or used outdated treatments. The Global Times, a nationalist tabloid owned by the official newspaper of the ruling Communist Party, called them "harmful hospitals."

Wu Xidong, executive president of the Putian health industry association, which oversees the group of private hospitals, defended its practices and operations. The public anger at Putian hospitals reflected dissatisfaction with poor regulation and the entire health care system, he said.

"The patients still give us recognition, isn't that correct?" Mr. Wu said. "This proves that we have no problems. The state has also not taken any measures against us, right? Because our hospitals themselves are very good."

Mr. Chen, 67, lives a quiet life in Dongzhuang after retiring in the 1990s from the health care empire he created. He drives his golf buggy around the temple complex, which has a statue devoted to Chen Jinggu, a woman who is revered in the area as the goddess of the land. None of the pilgrims seemed to recognize him.

Like other Putian tycoons, Mr. Chen has been keeping a low profile. He doesn't want to talk about the scandal but rails against the "misinformation" out there.

"The reports were nonsense. They were a mess," Mr. Chen said. "Now, when people go and see a doctor, they'll ask: 'Is this a private hospital? Should we go in?' There's a question mark. Will they be deceived? It's making things difficult for us."

"All of us were from Dongzhuang, and one by one, we started engaging in medicine," Mr. Chen said. "It was your relatives, his relatives — all of us were relatives." Bryan Denton for The New York Times

From Scabies to S.T.D.s

During the turmoil of the Cultural Revolution, doctors were scarce and medicine was limited. Scabies, an itchy, highly infectious disease caused by mites, afflicted many Chinese. "It spread like wildfire," Mr. Chen said.

Mr. Chen saw an opportunity, coming up with a homemade remedy — a combination of nitric acid, mercury and vinegar. Traveling throughout China, he sold it for 30 cents a bottle, 10 times the cost. Mr. Chen made about $2,200 a year, at a time when public servants earned about $5 a month.

“The country’s medical system was so backward,” Mr. Chen said. He attracted a core group of disciples, training them in his practice. “None of us had any medical background.”

For decades, the Communist Party provided the basics. In the countryside, legions of so-called barefoot doctors, medical professionals with limited training, treated farmers, with the government picking up most of the costs. In cities, most Chinese workers received coverage through their employers, state-owned companies.

When China’s paramount leader, Deng Xiaoping, started to open the economy in the late 1970s and introduce market reforms, he took away government subsidies for health care. “Barefoot doctors” lost their source of income, and hospitals were left to fend for themselves.

Mr. Chen and his apprentices started renting rooms in small hotels across from bus stations, where there was a lot of foot traffic. They posted ads on utility poles to target more customers.

In the decades that followed, Mr. Chen and his partners branched out, starting clinics to treat sexually transmitted diseases. Prostitution was on the rise, and people were embarrassed about going to public hospitals to be treated. The clinics allowed patients to register anonymously.

“S.T.D.s are embarrassing. You don’t want anyone else to know,” Mr. Chen said. “You could write down any name — we wouldn’t care.”

He and others in the Putian network soon developed a signature style, expanding widely with clinics in nonemergency fields like infertility, dermatology and cosmetic surgery. After clinics, they opened entire hospitals.

Mr. Chen bowed out of the business in the 1990s, after a car accident. The network continued to flourish.

The group got a major boost from the government in 2003, when China granted private hospitals tax-free status for three years. Severe acute respiratory syndrome had swept the country, forcing the authorities to scramble to get more hospital beds and build more quarantine facilities. And officials realized the public hospitals were insufficient to care for the rapidly swelling population.

A decade later, the government, at a meeting of the top party leadership, said it would further encourage the development of private hospitals. Chen Zhili, former vice chairwoman of the National People's Congress, wrote a letter to the Putian network in 2014, thanking it for "making positive contributions to the development of private medical care in China."

The government backing attracted interest from Wall Street. American financial firms like Sequoia Capital and Morgan Stanley have invested billions of dollars in health care companies in the Putian network. Several of the companies listed their shares on the stock exchanges of Shanghai and Hong Kong.

Steven Wang, founder of HighLight Capital, a private equity fund in Shanghai, said he had first heard about the Putian network from his parents, both doctors in public hospitals. When Mr. Wang visited the city of Putian in 2001, he found a place still mired in poverty, but he was impressed by the spirit of the locals.

Centuries earlier, the city had been invaded by Japanese pirates. A massacre followed, and people fled to the mountains. They were a people, Mr. Wang said, who could "eat bitterness," referring to an expression used by Chinese to describe the ability to endure hardship.

Mr. Wang invested $150 million in the Putian-linked Angel Group (China) Holding Company, which runs a maternity hospital in the southwestern city of Chengdu. He said the second generation of entrepreneurs from Putian, who followed Mr. Chen and the initial founders, were mostly university educated. So their

"knowledge, insights and vision" are different from those of their forebears, Mr. Wang said.

"They are full of vitality, are keen to learn, are open-minded and want to improve," he said.

Xing Jiaming, a former Putian intern, said he had been told to make up résumés of doctors and testimonials from patients. Bryan Denton for The New York Times

Patina of Legitimacy

Xing Jiaming was excited in 2015 to start his internship at a marketing firm for Putian hospitals in the cities of Nanjing and Jinan. As an economics student, he thought it would be useful to gain some other experience, especially at a fast-growing business. Over the previous decade, more than 9,000 private hospitals had opened in China, most connected to the Putian group.

During his first week at work, he got a plum assignment. A doctor had recently left one of the hospitals, and Mr. Xing was assigned to write up the credentials of the doctor's replacement. The résumé of the replacement was identical to his predecessor's. When the intern asked about the similarities, his boss told him to finish.

For the Nanjing Brain Hospital, Mr. Xing said, he was told to promote its treatment success rate as 100 percent. He also made up testimonials, including

one of a woman in Nanjing who was cured of anxiety after going to a Putian-related hospital.

"Everything was fabricated by us," he said. "None of them was a real case."

Mr. Xing said he and his colleagues had been given templates. "We had to exaggerate the harm caused by the disease," he said. "The more exaggerated, the better." The company, he said, had a "professional art team" that would steal online photographs of other people and stick them onto testimonials.

Mr. Xing resigned after two weeks.

"This phenomenon doesn't only pertain to the Putian network, right?" Mr. Wu of the Putian health association said. "All over the internet, it's likely that there are many other businesses who engage in that."

Putian tapped the power of the internet to expand, plowing profits into marketing. Liang Jianyong, a former Communist Party secretary in Putian, said the network invested $1.8 billion in advertising on the Chinese search giant Baidu in 2013. It amounted to nearly half the search engine's advertising revenue that year, according to the National Business Daily. Baidu declined to comment.

Many of the online marketing materials have a similar feel. They feature dozens of specialists, with lengthy résumés promoting "abundant clinical experience" and "praise from peers within the industry." There are glowing testimonials from satisfied patients with emotional narratives.

One details the case of a father who "knelt down" pleading with the chief doctor at the Putian-linked Edward Hospital, in the far western region of Xinjiang, to treat his 5-year-old daughter. She received treatment that was "the most advanced technology in the world."

Some Putian hospitals promoted credentials they didn't have. Two of the nine doctors advertised on Shenyang Metropolis Hospital's website are not accredited to work there, according to an analysis of a doctor database run by the National Health and Family Planning Commission, the government agency.

Others tried to make it seem they were affiliated with some of the country's top hospitals.

Weining He Mu Jia, one of the 8,000 hospitals in the Putian network, had the patina of legitimacy. He Mu Jia was the Chinese name of Beijing United Family Hospital, China's first foreign-owned hospital and one of its most respected.

President Barack Obama and Gary F. Locke, a former United States ambassador to China, graced the covers of Weining He Mu Jia's magazines. A photo of Roberta Lipson, the founder of Beijing United Family Hospital, hung in the Weining hospital's lobby. The photo, which was doctored, featured Ms. Lipson at the grand opening of the emergency room expansion of the "Weining United Family Hospital and Clinics."

The connections were purely show. Despite no relation, more than 20 hospitals in the Putian network have used the Chinese name He Mu Jia or similar variations, according to Ms. Lipson. Her company, Chindex International, has sued six Putian hospitals for trademark infringement, including Weining He Mu Jia.

"Every single day in the news, there are people on the internet complaining about them, complaining about malpractice, and it's our name," Ms. Lipson said.

Beijing United won the trademark infringement lawsuit against the Weining hospital in 2014. But Weining still runs an account on Weibo, China's version of Twitter, with the He Mu Jia name.

Putian properties are scattered throughout Dongzhuang. Mr. Chen, who lives quietly there in retirement, denounced the "misinformation" about the Putian network. Bryan Denton for The New York Times

A Scandal Erupts

Wei Zexi, a 22-year-old university student, was lured by the promises of a Putian hospital.

With a diagnosis of synovial sarcoma, a rare form of cancer that attacks the tissue in the muscle joints, Mr. Wei had undergone three operations, four chemotherapy sessions and 25 radiation therapy sessions and had taken traditional Chinese medicines hundreds of times. With the help of donations, he bought Keytruda, an immunotherapy drug that is not available in most parts of the mainland, for $5,000 in Hong Kong.

When none of it worked, Mr. Wei desperately looked online for options. A Putian center at a military hospital in Beijing, appearing at the top of his search results on Baidu, offered what seemed like a miracle: an immunotherapy program called DC-CIK.

"As long as you have 1 percent of hope, it is worth using your life to take a gamble," he wrote in a May 2015 reply to a post on Zhihu, a Chinese knowledge-sharing website.

A doctor, a specialist for the Putian treatment center, Shanghai Kangxin hospital management company, told him that the DC-CIK treatment had a success rate of 80 to 90 percent and could extend his life by 20 years. He touted a partnership with Stanford University.

His parents borrowed money from relatives and friends for the four treatments, which cost $30,000. Within a few months, the cancer had spread to his kidneys. In April 2016, 19 months after he first sought treatment in the Putian-linked hospital, Mr. Wei was dead.

The DC-CIK treatment had been phased out in the United States because it was largely ineffective. There was no partnership with Stanford.

Mr. Wei, according his best friend, Wang Xi, believed the treatment was legitimate because of Baidu's search results. The influential state broadcaster China Central Television had also once interviewed the doctor who treated Mr. Wei.

"He felt he was already cautious enough," his friend said.

A nationwide scandal erupted after his death. The Putian network became the emblem of unfettered corruption within the private health care system. Local authorities took particular aim at one of its more egregious violations, operating clinics within other hospitals. The practice had been outlawed years earlier, but many players in the Putian network continued to develop them.

In 2017, a court in Anhui Province said a hospital had violated local regulations by renting out several specialist departments in andrology and dermatology, among others, to a man from Putian, who was eventually forced to shut down. That same year, the local governments in the provinces of Liaoning and Henan announced crackdowns on the practice.

"China's health care fraud is pretty rampant," said Dr. Ma Jun, director of the Harbin Institute of Hematology and Oncology, a public hospital in China's northeast. "With China's private hospitals, there are a lot of traps."

In October 2016, Chen Zhanghao paid $580 for nasal surgery in the eastern city of Ningbo at what he believed was a subsidiary of Tongren Hospital, a prestigious hospital in Beijing. He had found the Putian-affiliated hospital on Baidu.

According to Mr. Chen, the hospital at the time purported on its website to be a Tier 3 institution, the government's top classification. Later, Mr. Chen learned, through a freedom of information request, that the hospital did not have the designation and was not allowed to conduct that type of surgery, according to a copy of the government's response to his request, which was viewed by The Times. (The hospital has since removed the classification.)

Mr. Chen, 25, now has difficulty breathing sometimes because his nose either hurts or is congested, he said. He tried looking for the doctors who had treated

him, but they have left the hospital, now known as the Ningbo Yinzhou Tongren Hospital.

Mr. Chen has nightmares thinking about his surgery. “I just don’t want to think about it anymore,” he said.

In March 2017, he joined five other patients with similar problems, protesting outside the offices of Baidu for compensation. They held banners that read: “We are the living Wei Zexis.”

Chen Zhanghao discovered after he had nasal surgery at a Putian hospital that it wasn’t classified to perform the procedure. Bryan Denton for The New York Times

Back at his temple, Chen Deliang defended the health care empire that he founded all those decades ago.

Mr. Chen said the hospital department that Mr. Wei had visited in Beijing had nothing to do with Putian but was owned by a company from Zhejiang Province. He did not elaborate, and corporate records showed otherwise.

When asked about the fake ads, Mr. Chen defended them, saying all ads need to have an element of “boastfulness,” but added that “it’s impossible that they are fake.”

He said many Putian hospitals had lost money, struggling to get loans and pay their workers. But when asked how many exactly, he said he could not tell for

sure.

"We are not selling fake drugs, nor are we deceiving people," Mr. Chen said. "The government has done nothing to us."

Research was contributed by Zhang Tiantian, Amy Cheng, Tang Yucheng, Elsie Chen and Ryan McMorrow.

Sui-Lee Wee has been a correspondent for The New York Times in the Beijing bureau since October 2016. She covers business in China, Chinese consumers, health care and the intersection of demographics and the economy. More about Sui-Lee Wee

A version of this article appears in print on , Section BU, Page 1 of the New York edition with the headline: Scandal and Fortune in China's Hospitals

Lele Tao

Dear ENS Patients:

the China ENS patients were suffered by BAIDU's fake medical advertisements, we want to take legal action against BAIDU in USA , so we are looking for a best lawyer in USA, who can help us on this issue? we will raise this fund to Dr.Atala for the reserch of ENS turbinate regeneration if Chinese ENS patients win the lawsuit. please help us to find a best lawyer in USA!

Sunny

my e-mail: 13764383009@163.com

5 comments

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Most relevant

Steve Chalklen

Sulin Sun are you sure you are not a scam looking for more money. I'm sure it was you who emailed me saying u have 90-000 pounds in account !

6y Like Reply

Steve Chalklen

No your right I'm not sure we al best give this girl money seems very legit

6y Like Reply

David Drew

She did not ask for money from the paragraph. She is asking for information about the best attorney in US.

6y Like Reply

Write a reply...

Patrick Galicki

True, no request for monies in the post. Who in America England and Australia actually comprehends English? 😊 Also, maybe this explains why I couldn't find any info on one guy I read about in the U.S. media that went to China for ens treatment. Bad result? Don't want to speak out? Too afraid or ashamed? I lost 20,000 usd on Indian ens treatment with good results that lasted jus 4 weeks. Was then asked for more money and had to speak out. Life's too short to be small [or shy]. Gotta be real.

6y Like Reply

Steve Chalklen

All this treatment appears to be short lived m. I had 3-4 good month ! Appears unless your a millionaire your fucked

Lele Tao ...

·

大家好!
这些年，空鼻症患者的病情都在加重，有些前几年不干燥的患者这几年开始出现鼻子干了，和干燥一起伴随的还有失眠，呼吸困难，越来越没力气，很多人已经上不了班了，凑合上班的也只能干一些相对简单轻松的工作，还得忍受身体的各种不舒服。很多时候我们觉得哪怕是缺胳膊少腿都比空鼻症幸福亿倍，空鼻症这个病是要人命的，痛苦那就更不用说了。空鼻症导致鼻神经失常，鼻子神经传导又影响着呼吸心跳、植物神经、内分泌代谢等，很多人心肺不能正常运行，肺功能不好、心脏不好，气血不能正常运行合成，严重的出现窒息缺氧、无力、失眠。忍受不了的患者绝望自杀，估计得癌症都没这么折磨人，令人绝望。因为没人研究再生，没有缓解办法，病情还在一直加重，患者越来越绝望，几乎每个空鼻症患者的内心都有自杀的念头和行为。但生命毕竟只有一次，我们还有家人，所以我们还是希望活着，希望能有一条生路。患者尝试了很多办法后基本以失败告终，切掉的东西吃药打针长不出来，除了再生几乎别无他法。

我们这个病的患者大都被切除了鼻甲海绵体和表面黏膜，所以需要再生鼻甲黏膜下海绵体和表面黏膜。

这段时间我们患者群体一直在讨论一些现实可信的办法，后来觉得指望3D打印再生鼻甲有点遥远和难以实现，尤其是海绵体血管丰富，且多是微小的血管，不是大血管，而且没有规则的组成血管窦，单纯的3D打印很难实现。

我们想到一个现实可行的办法：能否用动物或死人的鼻甲脱细胞做支架，再把患者的血管内皮干细胞附到支架上，成活后就是海绵体了（海绵体主要是血管）。
黏膜再生也是利用脱细胞黏膜支架，再把患者的鼻粘膜上皮干细胞附到支架上，成活后就是鼻粘膜了。因为鼻黏膜上皮细胞有好几种细胞，那么是否可以测算一下这几种细胞在鼻黏膜上的构成比例，那么再把这几种上皮干细胞配比混合后附在黏膜脱细胞支架上，是不是就可以生成一个鼻黏膜了?

鼻粘膜下就是海绵体，这两个再生研究是不是可以一起做，实在不行再生海绵体也能解决空鼻症患者的很多问题，至少血供问题解决了，黏膜有可能恢复一些功能。

以上是我们自己看书查资料结合自己病情琢磨的一个方案，不知道现实中是否可行?
如果可行，我们能否在Go fundme 和Facebook上发起募捐，募集的资金给科研机构研究鼻甲再生?

Hello everyone:
In recent years, the condition of ENS patients is aggravating. Some patients who have not been dry for a few years have begun to dry. Together with dryness, they also suffer from insomnia, difficulty breathing, and lack of strength. Many people can't work due to ENS, someone can only do some relatively simple and easy work, sometimes we feel that even if we lack arms and legs, we are 100 million times more happy than empty nose. The disease of empty nose is life-threatening. ENS causes nasal nerve disorders, nasal nerve conduction affects respiratory heartbeat, autonomic nerves, endocrine metabolism, etc. Many people's heart and lungs can not work normally, lung function is not good, heart is not good, Air and blood can not be normal synthesis, and some serious patients are suffering from suffocation, dizziness and weakness, insomnia. The patients who can't stand it is desperate to commit suicide. It is estimated that the cancer is not so tormented and desperate. Because no one studies turbinate regenerative, there is no mitigation, the condition is still increasing, the patients is more and more desperate, and almost every person with ENS has suicidal thoughts and behaviors. But life is only once, we have family, so we still want to live, hoping to have a way to live.
Most of ENS patients have been cut the cavernous body and surface mucosa, so it is necessary to regenerate them. China patients group has been discussing some realistic and credible methods these days. I feel that it is very difficult to achieve 3D printing for cavernous blood vessels, because most of them are tiny blood vessels, not large blood vessels, and there are not arrangements in rule. The composition of the vascular sinus, simple 3D printing is difficult to achieve.

We think of a realistic and feasible way: whether the animal or dead man's turbinate can be used as a scaffold after decellularization, and then the patient's vascular endothelial stem cells are attached to the acellular scaffold. it will regenerate the sponge body (the sponge is mainly a blood vessel) if it is successful.

Mucosal regeneration is also the use of acellular mucosal scaffold, and then the patient's nasal mucosal epithelial stem cells are attached to the scaffold, it will regenerate the nasal mucosa if it is successful. Because there are several kinds of cells in the nasal mucosal epithelial cells, if Research institutions measure the proportion of these cells on the nasal mucosa, then mix these epithelial stem cells and attach them to the mucosal decellularized scaffold. Is it regenerate nasal mucosa?

Under the nasal mucosa is the cavernous body. Can these two regenerative studies be done together? It is impossible to regenerate the cavernous body to solve many problems of patients with empty nose. At least the blood supply problem is solved, and the mucosa may restore some functions.

The above is a plan for us by read the book and check the information combined with our own illness. it is feasible in reality?

If it is realistic and feasible, can we raise money on Go foundme and Facebook for ENS research? We can raise the funds to research institutions to study the regeneration of the turbinate.

> 大家好!
> In these years, empty nose disease patients are getting worse, some patients who did not dry in the past few years began to have dry nose in the past few years, and dryness is accompanied by insomnia, difficulty breathing, more and more weak, many people can't go to work, can only do relatively simple and easy work, and have to endure various physical discomforts. Many times we feel that even missing arms and legs are billions of times happier than empty nose disease. The disease of empty nose is deadly, not to mention pain. Empty nose disease causes nasal nerve disorders, nose nerve conduction affects respiratory heartbeat, plant nerves, endocrine metabolism, etc. Many people's heart and lungs can't function normally, lung function is not good, heart is not good, qi and blood can't function properly, serious asphyxia, hypox Patients who can't stand desperate suicide, estimated cancer is not so painful, desperate. Because no one studies regeneration, there is no way to relieve, the condition is still getting worse, the patients are getting more and more desperate, almost every empty nose patient has suicidal thoughts and behaviors But after all, we only have one life, we still have family, so we still want to live, hope we have a way to After trying many methods, the patient basically failed, cutting off the things, taking medicine and injections can't grow out, and there's almost nothing else to do except regenerate
>
> Most of our patients with this disease have been removed from the nasal sponge and surface mucosa, so we need to regenerate the submucosa and the surface mucosa.
> During this time, our patient group has been discussing some realistic and reliable methods, and later felt that it was a little remote and difficult to achieve 3D printing to regenerate nasal nails, especially the sponge body blood vessels are rich, and mostly tiny blood vessels, not large blood vessels, and there is no regular composition of blood vessels, simple
> We came up with a realistic solution: can we use animal or dead human nasal arthritis cells as a scaffold, and then attach the patient's vascular endothelial stem cells to the scaffold, and become a sponge (the sponge Mucosal regeneration also uses a decellular mucosal scaffold, and the patients' nasal mucosal epithelial stem cells attached to the scaffold, and after survival Because nasal mucosal epithelial cells have several types of cells, can we measure the composition of these cells on the nasal mucosa, and then mix these types of epithelial stem cells and attach them to the mucosal decellular scaffold, can we create a nasal m
> Under the nasal mucosa is the sponge body, can the two regeneration studies be done together, really can not regenerate sponge body can solve many problems of empty nasal patients, at least the blood supply problem is solved, mucosa may restore some functions
> The above is a plan for us to read books and check data combined with our own illness. I don't know whether it is feasible in
> If possible, can we raise funds on Go fundme and Facebook to research nasal nail regeneration at scientific institutions?
>
> Hello everyone:

In recent years, the condition of ENS patients is aggravating. Some patients who have not been dry for a few years have begun to dry. Together with dryness, they also suffer from insomnia, difficulty breathing, and lack of strength. Many people can't work due to ENS, someone can only do some relatively simple and easy work, sometimes we feel that even if we lack arms and legs, we are 100 million times more happy than empty nose. The disease of empty nose is life-threatening. ENS causes nasal nerve disorders, nasal nerve conduction affects respiratory heartbeat, autonomic nerves, endocrine metabolism, etc. Many people's heart and lungs can not work normally, lung function is not good, heart is not good, Air and blood can not be normal synthesis, and some serious patients are suffering from suffocation, dizziness and weakness, insomnia. The patients who can't stand it is desperate to commit suicide. It is estimated that the cancer is not so tormented and desperate. Because no one studies turbinate regenerative, there is no mitigation, the condition is still increasing, the patients is more and more desperate, and almost every person with ENS has suicidal thoughts and behaviors. But life is only once, we have family, so we still want to live, hoping to have a way to live.
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1

Lele Tao ···

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控告书 我叫孙素林，女，汉族，1971年出生 现居住于：上海市松江区，我来自一个军人老干部家庭，我的丈夫是中国人民解放军第四野战军军官的后代，但是我却被深深热爱的中国人民解放军军队医院——上海解放军85医院及中国最大的搜索引擎百度给害了。

我要控告：百度集体公司、 打着85医院名誉做医疗广告的科室外包者中国莆田系林新太、林建国及其诈骗公司及非法行医人员：解玉华 张伟 李晶夏晓维等，虚假广告罪、故意伤害罪、非法行医罪，被控告人对我原本健康的鼻子故意做了十多项手术进行故意伤害，造成了无法挽回的严重后果。
我之前身体健康，没有其他毛病，亦无家族遗传疾病，耳鼻喉检查完全健康，无任何鼻炎、鼻甲肥大、咽炎，有2012、2013年6月份体检报告为证。
我从2013年9月左右开始外耳道瘙痒，在多家公立三甲医院治疗依然瘙痒，夜里瘙痒难忍不得不半夜起来用棉棒掏耳朵缓解瘙痒，我也不清楚问题出在哪里，就想再换一家看看。
为了查找其他合适的医院、医生、病因、症状及治疗方法，我就通过百度旗下的hao123网络进行查找及搜索，由于85医院在网页前面，第一眼就是军队公立三甲的字眼，且百度及其推广网页里对医院、医生、设备、治疗方法都介绍的很好，出于从小以来爱国爱党爱军队的信仰，加上生活在一个老干部家庭，更是对部队有特殊的感情，对部队医院无条件的信任，我于2013年12月8日到解放军85医院五官科看耳朵痒，门诊解玉华医生要求我做耳朵、鼻子、喉咙的内镜检查，检查做完后解医生说" 耳鼻喉连在一起，要发炎都发炎，你这耳朵痒就是鼻子、喉咙引起的，都得治，再不治耳膜马上就要穿孔了，那就麻烦了，赶紧治，鼻子、喉咙都得治，治好了你耳朵就好了，先治鼻子吧，……"。在解玉华的故意恐吓、欺骗、诱导下，且无病情及手术告知的情况下，85医院外包耳鼻喉科室人员给我的鼻子做了下鼻甲部分切除、中鼻甲部分切除等离子射频消融等多项手术（这是后来导致严重空鼻综合症后才知道），给我的耳朵也做了外耳道切开异物取出、微波、红外线等多项治疗，由于当时医生一直告诉我是治疗，且在门诊治疗室治疗，既没麻醉又没用手术刀，加上又没签知情同意书，当时真不知道是手术，治疗过程中没有疼痛根本不知道是实际上是等离子消融术，还有一个特殊原因，那就是我来自军队老革命家庭，对部队医生的特殊感情及信任，当时根本没有任何质疑。
这些所谓的"治疗"非但没有解决我耳朵的问题，反而出现鼻部的严重症状。在85医院治疗后不久，大约10天左右鼻腔内消肿后，我就感觉鼻部通气阻力很低、通气很大、冷空气直达肺部，并出现咳嗽、气喘、胸闷等症状，白天晚上不停的干咳，当时不知道这是鼻手术损害并发症，一直当支气管炎治疗，期间偶尔出现头晕无力、瞬间窒息的情况，到上海中山医院的一次例行检查中发现血小板就开始下降了（从200左右下降到为112）、肺功能轻度下降等。之后病情不断发展，出现鼻内干燥、鼻中部内剧疼难忍、鼻腔内空荡荡的、呼吸寒冷，头疼欲裂、咽喉火辣辣的干疼、鼻涕倒流，时常头晕没劲，瞬间窒息感、鼻子呼吸气流感越来越弱等一系列症状，为了缓解鼻子内部剧烈的疼痛，我不停的揉鼻梁，时常到洗手间一遍遍用冷水洗脸，不停的往鼻孔内喷药，先后用过生理海水，纳米银抗菌水凝胶喷剂，滴薄荷油、鱼肝油、AD制剂、香油、抹金霉素眼膏等，维生素也吃了一堆，甚至买了专用的洗鼻器，洗鼻剂清洗鼻子，但鼻子的症状不仅没缓解，反而在加重，同时头疼头晕的症状也在加重，由于疼痛欲裂，我无法干好工作，看电脑根本不能集中注意力，打字看图很吃力，稍一专注用心或思考，疼痛及眩晕就加剧袭来，精力也越来越不济，后来甚至回家都干不好家务活了，只好请了个四川阿姨料理家务。与此同时，鼻腔的呼吸气流感急剧减弱，我先是左侧没感知，然后是右侧气流感减弱，症状越来越重。这期间，我不清楚哪里出了问题，一直在上海的医院求诊。2014年3月15日，复旦大学附属眼耳鼻科医院诊为"空鼻症"。
2014年3月26日，我突然出现可怕的症状：鼻气流感突然完全消失，然后浑身越来越无力，瘫软无法行走。紧接着出现心慌、呼吸困难、强烈的缺氧窒息感如同一个上吊自杀濒临死亡边缘的人。喘不上气、呼吸不受控制、身体抽搐，体内器官出现内耗、奇热出汗，失眠无法入睡，浑身酸疼难忍，我无数次行走在死亡边缘，由于呼吸极度困难，很多次窒息、心肺堵的严重，哭喊挣扎都喘不出那口气来，母亲及爱人不得不轮流守候着我，一旦出现生命危险就就赶紧急救，不停按压胸部，按摩擀顺肺部胸部，直到我慢慢缓过气来，这种生不如死的非人折磨让人无法承受，无数次与死神的垂死挣扎，无数次面临窒息死亡，我只想马上了解生命，赶快解脱，多少次我都要挣扎爬起来从所在的13楼跳下去，去厨房拿刀抹脖子，但母亲

及丈夫一直在我身边拼死阻拦，一家人都陷入极度痛苦悲伤之中，此后我只能大部分时间躺着勉强维持生命，更无能力做任何事，生活也只能由家人陪护照顾，更无法上班工作。后来因无法上班，被我单位辞退了。

我此后在上海多家医院求治，但都不能求得有效救治。万般无奈我开始了国内外的漫漫求医之路，先后在北京武警总院、襄阳市中心医院、襄阳市中医医院、中山大学附一医院等多家医院诊治。在北京武警总院治疗时，诊断为：呼吸困难、双侧鼻甲萎缩，表面有长条疤痕、血系统多项指标不合格、血小板为56等，所以接受"空鼻症干细胞移植术"。在襄阳中心医院住院期间，血液化验仍然多项不合格，血小板甚至下滑到31，内脏等多器官出现疼痛，关节、背部、腰部也出现酸疼，我成了医院的危重病号。在多家医院治疗无效后，全家人都很绝望，甚至做了最坏的打算，我甚至做好了死亡的准备。

自85医院给我鼻部治疗损伤以来，我的身体就慢慢衰竭的历害，我的呼吸系统、肺、造血系统、肾脏系统、睡眠、骨骼等相继出现严重问题。每天头晕无力，走不动路、站不久、坐不久，完全丧失劳动能力，生活自理困难，天天由家人照顾，多器官功能出现严重问题，空鼻症导致肺功能严重下降、继发性心脏病、继发性糖尿病（血糖突然升高，平时不能超过5.7，否则就更喘不上气）、出现血尿、高铁血红蛋白高（引起窒息）、乳酸高（引起窒息）、鼻子干眼干（黏膜不停萎缩，窒息感越来越重）等。我时时刻刻都生不如死，炼狱一般的生活。想死、想自杀、想解脱是我每天都在考虑的问题，如果有安乐死我肯定毫不犹豫的选择离去，如果有把枪我早就对自己扣动了扳机，我实在太难受了，感觉人生走到了尽头。我时常想，哪怕缺一条胳膊或腿也比空鼻症好过亿倍，至少能自由呼吸，全身器官是好的，能舒舒服服活到自然死。可我们呢，前途路在何方？是自杀还是怎么自杀？哪怕中国有个安乐死也行啊，总比这看不到边的黑暗要好。

因为自2014年发病以来，全家几乎没有任何经济来源，孩子要上学、我又到处看病、家里还要生活，实在是走投无路，在2015年底迫不得已卖掉上海唯一的住房，这几年物价飞涨，房价翻了几番，以前180万的房子现在已是400多万，因为被害成空鼻症我们一家几代人辛苦努力的家业和积蓄化为乌有，我们夫妻辛苦大半生的劳动成果毁于一旦，健康没了，财富没了，事业没了，家也没了，上无力照顾赡养老人，下无力抚养儿女，因为奔波于看病及打官司我们几年无法回家，老人孤苦无依病死在家我们却不能在床前尽孝，孩子的学业也受到很大的影响，原本出国留学的计划也搁浅了，由于无法上班我们的五险一金被迫断交，基本的生活保障都没了，上海市户口也无法转了。

可我的案子民事诉讼从2014年进入法院拖到现在也没结果，没有得到任何赔偿，作恶的私人老板及非法行医的4个人依然逍遥法外，他们换个地方还在继续害人，百度不仅没得到任何惩罚而且莆田系虚假医疗广告更猖獗了，而我家却在地狱里煎熬，从中产阶级沦为穷困潦倒的家庭，我们现在走投无路，活不下去了。

后来查明：85医院在百度打广告的很多网址根本不是85医院，而是个人注册的网站，这是打着部队名义外包科室的私人老板。再者给我诊疗的几个人员根本没有执业资格证，其中有3人被认定为非卫生技术人员。

85医院科室外包人员使用部队名义在百度推广，进行虚假医疗广告和宣传；且使用解玉华、张伟、夏晓维、李晶等非卫生技术人员假冒军队医务人员非法行医，对原本无任何鼻病的我实施了十多项惨绝人寰的屠杀式鼻内部手术，给我造成了非常严重的人身伤害，致使我长期卧床、丧失劳动能力长期需要家人护理照顾。

被控告人的一系列行为已严重触犯了《中华人民共和国刑法》第222条　【虚假广告罪】广告主、广告经营者、广告发布者违反国家规定，利用广告对商品或者服务作虚假宣传，情节严重的，处二年以下有期徒刑或者拘役，并处或者单处罚金。第231条 单位犯本节第221条至第230条规定之罪的，对单位判处罚金，并对其直接负责的主管人员和其他直接责任人员，依照本节各该条的规定处罚。第234条　【故意伤害罪；】故意伤害他人身体的，处三年以下有期徒刑、拘役或者管制。致人重伤的，处三年以上十年以下有期徒刑；致人死亡或者以特别残忍手段致人重伤造成严重残疾的，处十年以上有期徒刑、无期徒刑或者死刑。第336条　【非法行医罪】未取得医生执业资格的人非法行医，情节严重的，处三年以下有期徒刑、拘役或者管制，并处或者单处罚金；严重损害就诊人身体健康的，处三年以上十年以下有期徒刑，并处罚金；造成就诊人死亡的，处十年以上有期徒刑，并处罚金。《医疗广告管理办法》第20条未取得《医疗机构执业许可证》发布医疗广告的，按非法行医处罚。

我曾多次向长宁区公安局报警及到长宁区检察院、法院请求立案，但均遭拒绝，我为了维护自身的合法权益，特在网上向公安局、检察院、法院提起控告，请求依法进行立案侦查公诉为盼！

2016年魏则西事件后，我才意识到被百度侵权了，于是到海淀区法院提起诉讼，直到2017年底才通知可以立案，但现在一审还没结案。
刚才打电话联系了海淀区法院郭振华法官的助理及中关村法庭的联络人，希望庭审直拨，但却没有结果，我的心情久久不能平静，感觉老百姓打官司太难了，我的案子这么多年过去了，一晃好多年了，都快一代人过去了还没个结果，受害者起诉百度莆田系需要十年二十年都没有结果吗？一个案子一辈子一审都没有结果吗？感觉对中国法制越来越失望，人生有多少年？年纪大的人估计等不到案子有个结果已经去世了，我们还有多少时间、耐心、精力、金钱去等等待？如果在欧美会有什么结果？违法者敢这么猖狂吗？受害者会这么绝望无助吗？法律是这么苍白无力吗？国外百度莆田系只怕早就破产坐牢了吧，哪还有可能让谋财害命者逍遥法外、成为亿万富豪？这就是老百姓期待的法制社会吗？这是让老百姓深深的失望，这是鼓励犯罪份子作恶……这是激化社会矛盾，让老百姓看不到希望……我们还会那么傻傻的热爱生活热爱生命热爱一切吗？……

控告人：孙素林
一个来自中国人民解放军第四野战军军官家庭的后人

> Indictment My name is Sun Sulin, female, Han, born in 1971. I am living in Songjiang District, Shanghai. I come from a family of veteran military cadre. My husband is the descendant of officers of the Fourth Field Army of the Chinese People's Liberation Army, but I have been hurt by the deeply beloved People's Liberation Army Military Hospital, Shanghai People's Liberation Army 85
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> I would like to sue: Baidu collective company, the department outsourcer who ran medical advertising under the reputation of 85 hospitals, Lin Xintai, Lin Jianguo, his fraud company and illegal medical practitioners: Xie Yuhua Zhang Wei, Li Jingxia Xiaowei, etc. The crime of false advertising, intentional injury, illegal medical practice. The accused deliberately performed more than ten operations on my original healthy nose, causing serious consequences.
> I was in good health before, no other problems, no family genetic diseases. ENT examination is completely healthy, no rhinitis, large nose nails, pharyngitis, as confirmed by the medical examination report of June 2012 and 2013.
> I started external ear canal itching around September 2013. I still treated itching in a number of public three hospitals. I couldn't bear to get up in the middle of the night with a cotton stick to relieve itching. I don't know where the problem is. I want to change it.
> In order to find other suitable hospitals, doctors, causes, symptoms, and treatments, I used Baidu's hao123 network to search and search. Because 85 hospitals are in front of the web page, the words of the military's public three-class military public service were first seen at first glance, and Baidu and its promotion webpage are very good about hospitals, doctors, equipment, and treatment methods. Out of the belief that patriotic love the Party and love the military since childhood, plus living in a family of old cadre, I also have special feelings for the military. I have unconditional trust in the military hospital. I went to the People's Liberation Army 85 Hospital to see ear acne. On December 8, 2013, Dr. Xie Yuhua asked me to do endoscopy of ears, nose, throat ". Under Xie Yuhua's intentional intimidating, cheating, and induction, and without any notice of the illness or surgery, staff from the otolaryngology department of 85 hospital outsourced ear, nose and throat department performed a number of surgeries on my nose, including partial removal of the lower nose, partial removal of the middle nose, radio frequency ablation of the middle nose (this was later known after causing severe empty nose syndrome). My ear also had external ear canal cut-out, microwaves, infrared and other treatments. Because at that time, the doctors had always told me to treat me, and I was treated in the outpatient treatment room, neither anesthesia nor a scalpel was used, nor signed the informed consent form. At that time, I really didn't know
> These so-called “treatment” didn’t solve my ear problems, but had serious symptoms in the nose. Shortly after treatment at 85 hospital, after about 10 days of intra nasal swelling, I felt that the resistance of nasal ventilation was very low, the ventilation was very large, the cold air reached the

lungs, and I had symptoms such as cough, asthma, chest tightness. I had a dry cough during the day and night. I didn't know this was a complication of nasal surgery. I had been treated for bronchitis. During a routine examination at Shanghai Zhongshan Hospital, I found that platelets began to drop (from 200 to 112), and lung function slightly decreased. Afterwards, the disease continued to develop. There was dryness inside the nose, severe pain in the middle of the nose, empty nasal cavity, cold breath, cracked headaches, hot throat dry pain, nose backflow, often dizzy, instant suffocating, nose breathing, flu, and so on. In order to relieve the intense pain inside the nose, I kept rubbing the bridge of my nose. I often went to the bathroom to wash my face with cold water, constantly spraying medicine into the nostrils. I used physiological seawater, nano-silver antibacterial hydrogel sprays, peppermint oil, AD preparation, fragrance oil, and smelly, etc. I also ate a bunch of vitamins and even bought it. At the same time, the nasal respiratory flu has been reduced dramatically, I didn't perceive it on the left side, then the right side air flu has been reduced, and the symptoms During this period, I don't know what went wrong, I have been seeking treatment at the hospital in Shanghai On March 15, 2014, Fudan University Affiliated Eye, Ear and Nose Hospital was diagnosed as "empty nose disease". On March 26, 2014, I suddenly had horrible symptoms: the nasal flu suddenly disappeared completely, then I became more and more weak, paralyzed and unable to walk. Immediately followed by panic, difficulty breathing, strong hypoxia asphyxia like a person on the brink of death by hanging himself. I can't breathe, breath is not controlled, body convulsions, internal consumption of internal organs, heat and sweat, insomnia can't sleep, pain and pain, I walked on the edge of death countless times, due to extreme difficulty of breathing, many times asphyxiation, serious heart and lung blockage, I couldn't get that breath, mother and lover had to take turns waiting for me. Once life was in danger, they rushed for emergency rescue, kept pressing the chest, massaging the lungs and chest, until I slowly passed through. This inhuman torture of life was unbearable, countless times with death, faced with death, I just wanted to understand life immediately, hurry to get rid of it, how many times I have to struggle to get up from where I am. Later I was fired from my unit because I couldn't work. Since then, I have sought treatment at several hospitals in Shanghai, but I have not been able to obtain effective treatment. With no help, I started the long road of seeking medical treatment at home and abroad. I have been diagnosed and treated in many hospitals, including Beijing Armed Police General Hospital, Fuyang City Central Hospital, Fuyang City Chinese Medicine Hospital, Zhongshan University Hospital. During treatment at the Beijing Armed Police General Hospital, the diagnosis was: difficulty of breathing, atrophy of bilateral nasal armor, long scars on the surface, unqualified blood system indicators, platelets were 56 and so on. So I received "empty nasal disease stem cell transplantation". During the hospitalization of Fuyang Central Hospital, blood tests were still unqualified. Platelets even slipped to 31, internal organs, such as internal organs, soreness also appeared in joints, back, and waist. I became the hospital's critical illness number. After multiple hospital treatment failed, the whole family was desperate and even prepared for the worst, I was even ready to die.

Since 85 hospital gave me nose treatment, my body has been slowly failing, and my respiratory system, lungs, hematopoietic system, kidney system, sleep, bones, etc. have serious problems. Dizzy and weak every day, unable to walk, standing soon, sitting soon, completely lost the ability to work, difficult to take care of self-care, taken care of by family members every day, serious problems in multiple organ function, empty nose disease, secondary diabetes (sudden rise in blood sugar, usually not more than 5.7, otherwise you can't breathe), haemuria, high iron hemoglobin (causing asphyxia), high lactic acid (causing asphyxia), dry nose (mucosa constantly shrinking, feeling of asphyxiation), I'm not as good as death all the time, a life of purgatory. Wanting to die, trying to kill myself, wanting to get rid of it is my daily consideration. If there is euthanasia, I definitely choose to leave without hesitation. If there is a gun, I would have pulled the trigger on myself. I am so sad I often think that even missing an arm or leg is more than a million times better than empty nose, at least to be able to breathe freely, the organs of the whole body are good, and to live comfortably until natural death. But

what about us, where is the future? Is it suicide or how? Even if there's an euthanasia in China, it's better than the darkness that can't see

Because since 2014, the whole family has almost no financial source, the children have to go to school, I have to see a doctor everywhere, and I have to live at home. It is really a desperate way. At the end of 2015, I had to sell the only housing in Shanghai. Prices have skyrocketed in recent years, prices have doubled. The previous 1.8 million houses are now more than 4 million. Because the victims have become empty nose disease, our family's hard work and savings for generations have gone to nothing. The fruits of our hard work and work of our husband and wife are destroyed. The health is gone, wealth is gone, career is gone, the home is gone. The elderly are unable to take care of the elderly, and they are unable to raise their children. Because we can't go home for several

But my case civil lawsuit has been dragged into the court in 2014 and has not resulted. No compensation has been received. The private boss and the four people who illegally practiced medicine are still at large. They continue to harm people in different places. Baidu not only did not get any punishment but also the fake medical ads in the field are even more rampant. My family is suffering in hell, from middle class to poor families. We are now out of nowhere and can't live.

Later I found out: Many of the websites advertised by 85 hospitals in Baidu are not 85 hospitals at all, but personal registration websites, which are private owners who outsource departments in the name of the army. In addition, several of the people who treated me did not have any license to practice, and three of them were identified as non-health technicians

85 hospital department outsource personnel used the name of the army to promote fake medical advertisements and propaganda in Baidu. They also used non-health technicians such as Xie Yuhua, Zhang Wei, Xia Xia Xiaowei, Li Jing to fake military medical personnel to illegally practice medicine. They carried out more than a dozen horrific butcherous internal nasal surgeries on me who originally did not have any nasal diseases, causing me very serious personal injuries, causing me to be in bed for a long

A series of acts of the accused has seriously violated Article 222 of the Criminal Law of the People's Republic of China [Crime of False Advertising]. An advertiser, advertisement operator or advertisement publisher, in violation of State regulations, uses advertisements to make false propaganda about goods or services, if the circumstances are serious, shall be sentenced to fixed-term imprisonment of not Article 231 Where a unit commits the crime mentioned in Articles 221 to 230 of this Section, it shall be fined, and the persons in charge directly responsible and other persons directly responsible for the crime shall be punished in accordance with the provisions of the Articles Article 234 [Crime of intentional injury;] Whoever intentionally injures another person's body shall be sentenced to fixed-term imprisonment of not more than three Whoever causes serious injury shall be sentenced to fixed-term imprisonment of not less than three years but not more than 10 years; if he causes death or causes serious injury to a person by particularly cruel means, he shall be sentenced to fixed Article 336 [Crime of Illegal Practice of Medicine] A person who has not obtained the qualification to practice medicine illegally, if the circumstances are serious, shall be sentenced to fixed-term imprisonment of not more than three years, criminal detention or public surveillance, and shall also or shall only be fined; if serious damage to the health of the patient, he shall be sentenced to fixed-term imprisonment of not less than three years but not more Article 20 of the Measures for the Administration of Medical Advertisements, if a medical advertisement has not been issued by a medical institution's practice license, it shall be punished

I have repeatedly reported to the Changning District Public Security Bureau, and went to the Changning District procuratorate and court to request to file a case, but they were all rejected. In order to protect my legitimate rights and interests, I have made a complaint online to the Public Security Bureau, the procuratorate, and

After the Wei Zexi incident in 2016, I realized that Baidu was infringed, so I went to Haidian District Court to file a lawsuit, and I was not notified until the end of 2017, but the first trial has not yet

concluded
Just now I called Judge Guo Zhenhua's assistant of Haidian District Court and contact person of Zhongguancun Court. I hope the court hearing will be dialed directly, but there is no result. My mood can't be calm for a long time. I feel that it's too difficult for ordinary people to fight a lawsuit. My case has passed for so many years. It's almost a generation has passed without a result. Will it take Is a case in a lifetime without a result? Feeling more and more disappointed with the Chinese legal system, how many years is life? Older people can't wait for a result of the case to die. How much time, patience, energy, money do we have to wait? What will happen if in Europe and America? How dare the lawbreakers be so mad? Would the victim be so desperate and helpless? Is the law so pale and weak? Baidu's foreign country is only afraid of going bankrupt and going to jail. How can it be possible to let those who seek money get away and become billionaires? Is this the legal society that the people expect? This is a deep disappointment to the common people, it is encouraging criminals to do evil... This is to intensify social conflicts and make the people see no hope... Will we still be so silly to love life love life love life love everything?...

Complaint: Sun Sulin
A poster from the family of officers of the Chinese People's Liberation Army 4th Field Army

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Michael Frederick
How you doin today **Sulin Sun**?

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